

From the DEPARTMENT OF MOLECULAR MEDICINE AND  
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# **MEMORIES OF PAIN, ADAPTATION TO LIFE AND EARLY IDENTIFICATION OF STRESSORS IN PATIENTS WITH BURNS**

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“Life can only be understood backwards; but it must be lived forwards”

Søren Kirkegaard



*To my family*



## ABSTRACT

**Background:** Burn injury is an unforeseen event causing physical and psychological trauma for the person afflicted. Patients treated for burns commonly experience high levels of pain and anxiety related to burn treatment during burn care. During the first year after burn injury patients may still be coping with intrusive memories and struggle with daily problems related to physical limitations and body image dissatisfaction. Despite the trauma, most burn patients adapt well to life after injury but some are unable to readjust, resulting in persisting psychological symptoms.

The overall aim of this thesis was to investigate the patient's experience during burn care and at follow-up with focus on pain, body image, posttraumatic stress and coping and explore adaptation to life after burn injury.

**Methods:** Studies I and II were qualitative and interviews were conducted with 12 adult burn patients, 6-12 months post-burn, and explored burn patients' experiences of pain, coping and adjustment. Study III, focused on to culturally adapt and validate the Satisfaction With Appearance Scale (SWAP) into Swedish to be to be used in the context of burn care. Pre-testing of the questionnaire was conducted with 13 former burn patients and psychometric properties were tested in 90 respondents. In study IV, 52 burn patients were followed at the three months after discharge and 32 patients completed the six month follow up. A standardised clinical protocol was used for systematic assessment of posttraumatic stress disorder (PTSD), body image dissatisfaction and coping strategies. The follow-up included an intervention with a burn nurse to complement the existing program.

**Results:** Patients provide a multifaceted description of burn pain and many aspects of daily burn care are painful. In general, coping during hospitalization was characterised by efforts to "endure" the pain experience itself. Patients depict post-injury life as a struggle to live with the sequelae of a burn injury. This struggle involves various ways of dealing with a fragile body, with limitations to activities of daily living and emotional processing of the trauma. The Swedish version of the Satisfaction with Appearance Scale (SWAP-Swe) proved to be a reliable and valid instrument for assessing body image dissatisfaction. Higher body image dissatisfaction was found for female gender, for participants with moderate burns and longer hospital stay and participants who undergo surgery during burn care. Approximately half of the patients had a risk of developing PTSD three months after discharge from hospital, and body image dissatisfaction was found to potentially predict risk for PTSD during follow-up.

**Conclusions:** There is a need for increased focus on and the development of pain treatment for burn injury, especially with burn wound procedures. Psychosocial support for patients should be implemented in the future to support coping and to increase the patients' ability to adapt to burn injury. Body image dissatisfaction is a stressor after burn injury, and particular attention should be directed towards the female patients' and patients with more extensive burns. It is important to include patients with less extensive burns in early follow-up care since this group is at risk of developing PTSD.

**Keywords:** Burn injury, Pain, Patient perspectives, Body Image, Disfigurement, Cross-cultural adaptation, Questionnaire, PTSD, Adaptation, Coping





## LIST OF PUBLICATIONS

This thesis is based on the following papers, which are referred to by their Roman numerals in the text:

- I. Tengvall O, Wickman M, Wengström Y. Memories of pain after burn injury – the patient's experience. *J Burn Care Res.* 2010 Mar-Apr; 31(2):319-27.
- II. Dahl O, Wickman M, Wengström Y. Adapting to life after burn injury – reflections on care. *J Burn Care Res.* 2012 Sep-Oct;33(5):595-605.
- III. Dahl O, Wickman M, Wengström Y. The cultural adaptation and validation of a Swedish version of the Satisfaction With Appearance Scale (SWAP-Swe). *Submitted.*
- IV. Dahl O, Wickman M, Björnhagen V, Fridberg M, Wengström Y. Early assessment and identification of Posttraumatic stress disorder, Satisfaction with Appearance and Coping in patients with burns. *Manuscript.*

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## PAPERS I-IV



## LIST OF ABBREVIATIONS

TBSA	Total Body Surface Area
ABSI	Abbreviated Burns Severity Index
ABA	America Burn Association
NSAID	Non-Steroid Anti-Inflammatory Drug
BID	Body Image Dissatisfaction
PTSD	Posttraumatic stress disorder
IES-R	Impact of Even Scale-Revised
SWAP	Satisfaction with Appearance Scale
SWAP-Swe	Swedish version of Satisfaction with Appearance Scale
CBQ	Coping with Burns Questionnaire
TBSA-FT	The extent of full thickness burns
ICU	Intensive Care Unit
CBT	Cognitive behavioral therapy



# INTRODUCTION

This thesis is rooted in my desire to understand how burns affect patients in the long term and how to improve care for burn patients. Although I was focused on acute burn care of patients with burn injuries for the majority of my 20 years in nursing, I never learned what life was like for these patients after they left the hospital, or how they experienced their care. Through my work and encounters with patients, I have come to understand that a burn injury is, in itself, a transformational event, affecting the lives of patients long after the burn is considered to be “healed” and that the acute care these patients experience may influence their ability to adapt to life after the injury.

The care of burn patients poses a major challenge for attending nurses, in part due to the complexities of care demanded by burn injuries, and in part due to the relatively small volume of burn patients in many hospitals, which makes it difficult to gain experience and formulate evidence-based treatment guidelines.

As a nurse, it has been important for me to pursue a deeper understanding of the situation for these patients and to explore the pain phenomenon from various perspectives: to understand how patients experience pain, what factors affect this experience during their hospital stay and how we can help them in the best possible way. This curiosity led me to my first study; to create a deeper understanding of pain from the patients’ perspectives, how it could be described and how the patients cope with pain. Furthermore, I wanted to study how patients experienced their time after being discharged from hospital and how they adapted to life after burns (paper II). The experience gained from these studies guided me to study disfigurement and body image after burn trauma (paper III) and finally, to follow up and support patients after being discharged from the hospital (paper IV).





# BACKGROUND

## EPIDEMIOLOGY

Burn injuries pose a serious health problem worldwide, and burns caused by fire and flames resulted in about 195 000 deaths in 2002 (1). Scalding and electrical burns probably cause additional deaths, but global data regarding such injuries are unavailable. Incidence varies greatly among countries, and is highest in developing countries where open flames and liquid fuels are used for cooking, lighting and heating homes (1). Burns are a leading cause of morbidity, disfigurement and disability and about 11 million people worldwide required medical attention due to severe burns in 2004 (1).

Annually in Sweden, on average, 1 350 people sustain burns severe enough to require hospitalization, giving a rate of 155 patients/million inhabitants/year (2). The incidence of burn injuries in Sweden is low, even when compared with other high-income countries, and the number of hospital admissions has sharply declined over the past 15 years (2). Possible explanations may include knowledge about prevention, safer home environments (regulated hot water temperature, safe electricity, smoke detectors) and better treatment. Consequently, more patients can be treated on an outpatient basis. The median hospital stay is three days but there are significant differences in this figure between patients (2). The most common type of injuries causing burns that require hospitalization are hot liquid (43%), open flames (15%) and electricity (9%) (3). Two-thirds of burn patients are men (2). The greatest incidence (27%) is within children aged 0-4 years, but they also usually have less severe burns, usually caused by scalding, and the shortest length of stay (2). Other high-risk groups include the elderly, people with disabilities and people of low socioeconomic status and those having a history of medical problems (4). Self-inflicted burn injuries are reported to be at about 4% (5) in developed countries, although the prevalence was found to be 5,7% in an eight-year retrospective study in Finland (6).

Many of the burn patients are vulnerable which affects their ability to self-manage burn care and recovery. A number of previous studies indicate that there is an overrepresentation of individuals with premorbid psychopathology in adult burn patients compared to the normal population (7). Studies using validated interviews for psychiatric assessment reported that about 60% of burn-injured individuals were diagnosed with at least one lifetime psychiatric disorder prior to the burn (8, 9), and the prevalence of alcohol abuse or dependence was about 32%. Having a history of pre-injury psychiatric disorders is a risk factor, especially during the year before the burn, to aggravate the perceived outcome, both for psychological and physical aspects, one year after injury (10). This group of patients has also been shown to need longer hospital stays, need more surgical procedures and involve several disciplines in the burn care (11).

In a Finnish study concerning fire-related burns covering a 10-year period, results show that 14% of adult patients were suspected alcohol abusers and that acute alcohol consumption was involved in at least every fourth case (12). However, this result is considered to be a low estimate due to the fact that the information was mainly gathered by self-reporting methods (12). It is, however, obvious that alcohol plays a significant role in many fire-related injuries.

Until the year 2010, burn care was organised in Sweden in four University Hospitals; the burn centers at Karolinska, Uppsala, Linköping and Malmö. From 2010, acute care of severe burns has been concentrated in two national burn centers in Uppsala and Linköping. Approximately 80 adult patients receive care annually at the Burn Unit at Karolinska University Hospital and about 50 of these patients have moderately severe burns involving > 10% of body surface area or severe burns involving > 20% of body surface area.

## BURN INJURY

A burn injury means partial or complete damage of the skin after contact with heat. Many burn injuries are healed spontaneously, but for many, life-long scarring, often located to the face, neck and upper arms, is common (13). These areas are sensitive, both from a functional and from a cosmetic point of view (13). There are several physical consequences of a burn injury, which change the functional ability of the body and the sensitivity and visual appearance of the skin. Burn injuries also influence many other aspects of life as compared to the common population (14). These include restrictions in range of movement (14), mental function, work, and adapting to appearance (15). Most patients return to a good life, but for many, their injuries represent a major life-changing event. Recovery can be difficult for patients, and both the hospital stay and the post-burn period may be stressful. In addition to the psychological stress, patients are saddled with more or less permanent skin damage, altered appearance, pain, itching, heat intolerance and other disabilities (4).

Burn injuries are described in terms of the percentage of total body surface area (TBSA) burned (4). The burn wound is assessed according to depth and size. The depth of a burn injury depends on both the total thermal energy transferred to the skin and the exposure time. Most burn wounds are deepest in the center and more superficial at the periphery and comprise three zones: coagulation, stasis and hyperemia (16). Conditions in the zone of stasis are dynamic and can thereby change the burn injury. A partial thickness burn, if left untreated, can become a full thickness burn, which is why wound care and management are crucial (16).

Burn injuries can be classified and described as superficial, dermal or full thickness burns. A *superficial burn* involves only the upper skin layer, the epidermis. The skin becomes extremely red, painful and hypersensitive. Such burns heal by themselves, usually without scarring (17). A *dermal burn* is divided into superficial and deep dermal injury, and involves the epidermis as well as the upper layer of the dermis. A *superficial dermal injury* is characterised by blisters, weeping and hypersensitivity of the wound surface. Since the sensory nerves are undamaged, the wound may be painful, even though it usually heals within two weeks without scarring. In a *deep dermal injury*, the epidermis and most of the dermis are injured. Blistering may occur, but more commonly, decreased sensation of the wound surface and slow capillary refill are found. Deep dermal injuries take several weeks to heal and heal with scarring. Such injuries may also require surgery and skin grafting (17). A *full thickness burn* involves both the epidermis and the entire dermis. Skin grafting is usually required to treat such injuries, or they can be left to heal slowly from the wound edges. Capillaries, sensory cells and nerves are destroyed and capillary refill is absent, as is sensation. In full thickness burns, healing entails scarring and a tendency for scar contractures (18, 19).

The severity of a burn injury depends on more factors than just the percentage of total body surface area burned and depth of burn. Other factors that may have a negative impact on treatment and prognosis include: patient age (children and elderly), other medical conditions, and burn location (face, airways, hands, feet and genitals). Internationally, the Abbreviated Burn Severity index (ABSI), which is based on gender, age, presence of inhalation injury and/or full thickness injury and size (TBSA), is used to evaluate burn injuries and to predict mortality (20).

Burns can also be grouped according to size, depth and care needs. Sweden uses the following system according to the National Board of Health (21):

- 1) *Minor burns*. Superficial partial thickness burn in the 15-60 years age groups, covering < 10% of body surface area and not requiring treatment for shock or skin graft;
- 2) *Moderate burns*. Partial thickness burn covering <20% of body surface area, of which < 10% involves a full thickness burn that may require surgery. Hand burns requiring surgery are also included in this group;
- 3) *Severe burns*. Includes partial thickness burns covering > 20% of body surface area, of which more than 10% are deep or full thickness injuries requiring intensive and multidisciplinary care. High voltage electrical burns are also included in this group. Also categorised as severe burns are partial thickness burns covering more than 10% or full thickness burns covering more than 5% where other concomitant disease or tissue injury, or age < 15 or > 60 years, are present.

One set of definitions commonly chosen for most study populations are the guidelines for Burn Center Referral Criteria for those burn injuries that should be referred to burn centers (22), as illustrated in Table 1.

Table 1. Burn Center Referral Criteria. American Burn Association

Burn injuries that should be referred to the burn center include the following:

1. Partial-thickness burns of greater than 10% of total body surface area
2. Burns involving face, hands, feet, genitalia, perineum of major joints
3. Third-degree burns in any age group
4. Electrical burns, including lightning injury
5. Chemical burns
6. Inhalation injury
7. Burn injury in patients with pre-existing medical disorders that could complicate management, prolong the recovery of affect mortality
8. Any patient with burns and concomitant trauma (such as fractures) in which the burn injury is the greatest risk for morbidity or mortality
9. Burn injury in children in hospitals without qualified personnel or equipment for the care of children
10. Burn injury in patients who will require special social, emotional or rehabilitative interventions

## BURN CARE

According to the British Burn Association, the goal of treatment in burn care is to assist individuals to recover to the pre-injury state and for them to return to their place in society with unchanged potential (23). Burn care is often (24) described in three phases of varied duration for the patient. The *critical phase* begins immediately after the injury and is characterised by high technology and intensive care focused on maintaining vital functions, patient monitoring, fluid therapy, respiratory care (often requiring a ventilator) and wound treatment. This is followed by the *acute phase* (also labeled as the *healing phase*), which lasts until the superficial burn wounds have healed or deep wounds have been skin grafted. Multiple surgeries (revision of nonviable tissue and skin grafting) and repeated wound treatments (washing, showering, dressing changes), typify the patient's hospital stay. In addition to interventions to promote wound healing, pain relief, optimal nutrition and fluid balance, this care period is characterised by preventive measures to forestall complications (25). The acute phase may be partly bypassed in smaller injuries and typically lasts two to three days.

The *rehabilitation phase* is a lengthy process that may continue for several years until the patient receives maximal benefit from rehabilitation care, including reconstructive surgery (27). This is a remodeling phase where raised erythematous scar tissue subsides and tissue collagenases cease remodeling with softer and less erythematous scarring. The goal of the rehabilitation is to facilitate the patient's return to a life with the least possible physical and psychological stress. Rehabilitation includes activities to maintain or create mobility and muscle mass so that the patients regain the ability to take care of themselves in the best possible manner, are able to return to their previous daily activities and work, and are capable of living with social and cosmetic changes (24, 26). Adequate pain management and recognition of psychological issues are also an important component of rehabilitation after burn injuries (27). Nursing care, as well as physical and occupational therapy, are all important elements for the patient to maintain mobility, prevent contractures, use various assistive devices to improve their personal capability, and, at a later stage, use pressure bandages to facilitate mobilization and reduce the incidence of severe scarring. Rehabilitation is usually

carried out by a multidisciplinary team (28) but guidelines for structured follow-up programs are not commonly used.

## **PAIN IN BURN INJURIES**

Controlling pain presents a challenge for the initial phase of care from the emergency room care through to the rehabilitation phase of care. Most burn pain results from tissue damage and pain associated with burns is unquestionably intense (29). Thermal injuries induce a time-depending inflammatory response and changes in inflammatory mediator levels can explain the variability in intensity of burn pain over time (30). Nerve endings are principally intact in partial-thickness burns, but even deep burns (as full thickness burns) can be painful, even though the sensory nerves in the area have been destroyed (31). Initially, the patient may feel a dull pressure sensation/pain in the area. When nonviable tissue is subsequently replaced with granulation tissue, pain sensation to sharp stimuli returns, and there is a risk of neurogenic pain (31). Not only is the type of tissue damage with a burn injury likely to generate high levels of pain, but wound care and therapies can also generate levels of pain that are equivalent or exceed those experienced by the patient at the time of the injury (29).

Consensus in burn care exists on how to define the various types of pain that can be identified and treated during the hospital stay. *Background pain* is the type of pain mainly caused by the injury itself. It originates from the burn wound or from the donor sites (areas from which the skin graft is harvested), and may be experienced even when the patient is at rest. Such pain is more or less constant during the treatment period and most intense during the first 14 days following injury, but decreases in intensity as healing progresses (31, 32). *Procedural pain* (pain related to treatment) is activated by the therapeutic procedures associated with wound care and mobilization. This type of pain can be extremely intense (31, 33, 34). *Breakthrough pain* can be triggered by changes in body position or turning in bed. This pain is more intense than background pain and its spiking of pain levels, but is usually shorter in duration than background pain (31, 33, 34). *Post-operative* pain follows excision and grafting and is often worse at the donor site than in the grafted site. It can persist for about a week, or until the donor sites heal (35). *Chronic pain* is defined as pain which lasts longer than six months or more after wounds have healed and can be due to nerve regeneration and residual damage (i.e., neuropathic pain) (35, 36).

Pain intensity measured during hospitalization reveals great individual differences among patients, including different pain intensity in the same patient on different days. The background pain generally decreases in intensity during the hospital stay (31, 32), and can be most intense in women and patients with severe burns (32). The variations in pain severity are not related to age, socio-demographic characteristics of the patients or length of hospital stay (31). There is no correlation between pain intensity and deep burns, but superficial burns tend to be most painful during rest within the first week after injury (31). The most intense pain is reported by patients during wound treatment procedures, especially in patients with partial-thickness burns (31). Greater pain may intensify feelings of anxiety and worry and vice versa (31). Such ongoing reactions may explain why pain can increase and persists for extended periods of time among burn patients (31, 34).

Untreated pain has many negative consequences, such as impaired wound healing and inhibited gastrointestinal motility with resultant loss of appetite, nausea, vomiting and constipation (31). Pain results in sensitization to more pain, and increases oxygen consumption and levels of stress hormones. Untreated pain may result in loss of confidence in the care, as well as protracted problems relating to fatigue, chronic pain, sensory function, and paresthesia (numbness and tingling of the skin) (31).

It is important to treat pain proactively from the onset, using both pharmacological and pain-reducing strategies.

Previous studies have reported that a significant amount of burn patients (up to 52%) still had ongoing burn-related pain an average of 12 years after injury and that for many patients, pain continued to affect their rehabilitation (66%), daily lives (55%) and mood (37). The majority (96%) of patients could still recall pain that they had experienced during treatment and this indicates that pain has a central role in serving as a reminder of burn injury (37). An extensive review about burn pain and psychiatric sequel confirmed a link between greater levels of pain during burn care and psychological distress, illness, health-related quality of life and posttraumatic stress disorder (PTSD) two years after burn trauma (38).

## **Pain treatment**

There may be several reasons for inadequate pain management in burn patients. Many clinical trials have been based on small groups of patients because it is difficult to conduct multicenter studies due to the various treatment methods employed at different burn units. Other reasons are that intensity of pain is associated with wound care which varies widely over the phases of burn care and recovery, making it more difficult to estimate analgesic requirements (39). Critically ill patients, many of whom are unable to communicate, render possibilities for pain assessment limited and pain management may also be based more on local tradition than on evidence-based treatment methods (40), even if there is an increased number of pain management guidelines which have been developed and implemented (39).

*In pharmacological treatment*, the administration of opiates is standard care for burn pain (35, 37). Opiate receptor agonists are potent, provide a dose-dependent sedation and the benefits and risks of these treatments are well known by the burn care staff. Patient control analgesia (PCA) can be adequate in controlling background pain even if it fails to give satisfactory pain relief during mobilization (41). PCA allows the patient to retain some degree of control over their own care, which can increase wellbeing (37). Clonidine can be used to enhance the analgesic effect (35). Non-opiate analgesics, such as acetaminophen and non-steroidal anti-inflammatory drugs (NSAID: s), are commonly used in combination with standard opiates (33, 35) to reduce peripheral and central sensitization. NSAID: s are not recommended for patients who undergo extensive surgery because of their antiplatelet effects (33). Advanced wound care and dressing changes, as well as other painful procedures, can be carried out in general anesthesia providing good control of pain and anxiety (35).

There are several options for non-pharmacological treatment of pain in burns and these can be adapted to the patients' individual coping strategies as well as ability and wishes to participate in the care. Four types of diversion have been evaluated: 1) Distraction by music, playing games and conversations for adults; 2) Guided imagery, to create an imaginary scene to divert patients attention during procedures; 3) Hypnotic analgesia to alter states of consciousness, making it easier to change the perception of pain; and 4) Virtual Reality which helps patients divert attention away from the painful sensation by immersing themselves in a computer-generated environment (35). Relaxations (e.g. diaphragmatic breathing and progressive muscle relaxation) are used to lower arousal and to reduce unnecessary muscle tension (35). Cognitive-behavior therapy (CBT) aims to modify patients' thought processes or distract catastrophic thoughts of the painful experiences and make thinking more accurate and more useful (35). Based on clinical experience, the covering of the wounds (occlusive bandage), helping patients to find a comfortable position in bed and using elevation of hands and legs to decrease pressure from the damaged tissue can also decrease levels of pain and discomfort.

## **NURSING IN BURN CARE**

Burn care is affirmed as being multidisciplinary and based on the efforts of many members of various professions within the burn team. The burn team usually consists of senior surgeons, nurses, anesthesiologists, physical and occupational therapist, nutritionists, psychologists and social workers (4). A burn team has clearly defined and shared goals with well-defined tasks and each expert contributes their knowledge to the team to provide optimal care for the patient (4).

Nurses often maintain the daily continuous contact with the patient throughout hospitalization, plan nursing care together with the patient, and coordinate treatments to allow the patients to have daily rest and privacy (42). The nurse's role as a liaison and advocate for the patient is important for effectively coordinating care among all members of the burn team. The purpose of nursing care, based on the individual needs and abilities of the patient, is to restore, preserve and enhance health, prevent disease and illness, and to minimise suffering (43).

Generally, nursing care includes both a relationship- and a task-oriented aspect, which may alternately be the focus of the nursing interventions provided to burn patients (44). The burn nurse needs to have knowledge of intensive care nursing as well as psychiatric nursing (45), however, care of the burn patient may be perceived to be intervention-focused, because of its technical aspects and frequent wound treatments. In addition to medical-technical management and physical care, nursing skills encompass the ability to apply previous experience to help the patient find new ways to cope with the stressful situation and to make care personal and humane. The patient may experience receiving care in a private room and being isolated from other patients as stressful, and the patient's network of family and friends becomes an important asset to the patient. The nurse needs to inform and accustom both patients and family about the most effective methods of care to make it easier to adapt to the environment, and to support family and friends to participate in the care (24).

Different phases in the burn care require specific nursing interventions, but the common aspects throughout the care trajectory consist of wound care, management of pain and anxiety, infection control, and psychological support for self-care (45).

Nurses are often involved in the wound care (28) which provides an excellent opportunity to build a relationship with the patient and also to educate patients and relatives about burn care. Because teaching is an important task for nurses in burn care, instructions about positioning techniques, splinting protocols, exercise, skin and scar care are often included (45).

Relieving pain is also an important element of nursing in burn care. In order to achieve effective pain management, the nurse must work in collaboration with the patient and the burn team, and the nursing plan must include: reliable pain assessment, clear treatment goals, knowledge of the various treatment options, documentation and discussion of the care plan with the patient, and treatment evaluation (46). The ultimate goal for pain management is for the patient to achieve a balance between successful participation in activities of daily therapies and being comfortable enough to get needful rest and sleep. It is therefore necessary to take into account the patient's own resources, ability to cope and capacity for self-control when planning for nursing interventions linked to burn treatment (46).

## **THEORETICAL CONCEPTS**

In burn care, some concepts are central to understanding the patient's experience of the traumatic injury and its subsequent care. Pain and changes in body image are a consequence of burn injury and increase the psychological and emotional stress for the patient, which may affect adaptation and the need of support.

### **Pain**

Because pain is a significant issue for the patient with burns (as previously mentioned), it is described here from the theoretical point of view. Pain is far more than just a physical experience for people. Pain has an emotional component that is always significant and entails great suffering for the individual. The generally accepted definition of pain, as defined by the International Association for the Study of Pain (IASP), is: *"an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage"*(47). The pain experience is unique for each patient and it is the personal interpretation of the experience that counts (47). The nature of pain after burn injuries includes both biophysical explanations of pain and psychosocial aspects of pain. Any single model cannot explain the experience, meaning and effect of pain. Pain can be perceived as a stressor, both in a physical and a psychological manner; a force that puts real or perceived demands on the body, emotions, mind or spirit of an individual. Experience of threats to the patient's life or reminders of such threats may enhance the pain.

### **Body Image Dissatisfaction**

Burn wounds sometimes cause radical changes in body image and are often related to the type and significance of the wounds and the appearance and permanency of the



scars (48). Apart from the wounds themselves, patients are affected by the reactions of other people to the appearance of the wounds, and subsequently, their self-confidence and self-image can be adversely affected. Patients must also adapt to a new body image. Even if the burns affect a part of the body which is usually covered by clothing, the patient can experience constant stress for the fear of them being exposed (48). The body image model described by Price consists of three elements: body reality, body presentation and body ideal (49), discussed at length below.

*Body reality* is the real physical body, describing the way our body is constructed (objective observations of, e.g., height, weight and hair color). This aspect of the model is affected by both genetic inheritance and the environment. *Body presentation* refers to an individual's dress, adornment, and behavior and, within certain limits, it is possible to control body presentation and reflect on how this is received by the environment. *Body ideal* is defined as how an individual desires to appear (49). These three parts of the body image fluctuate during life and constantly affect each other. In particular, the body ideal is a very vulnerable part of self-identity as it is constantly changing and easily influenced. It is not only dependent on the person's own body, but also on attitudes and responses to perceptions from society (49). Burn injury affects all dimensions of body image where the body reality is wounded, leading to changes in body presentation and how the body is perceived by others. Body ideal affects patients' body images that are not only constructed within their internal world; we live in society and interact with family, friends and strangers who also contribute to constructing this image externally. The body image is also affected by the way we understand how others are treating us and by our perceptions that they are either accepting or rejecting us.

Body esteem (often defined as body image in the literature) is a multidimensional concept that relates to a person's physical appearance and the degree to which a person is satisfied with his/her appearance. These changes in appearance and function also affect social adjustment and social integration, either by acceptance or stigmatization (50).

Body image dissatisfaction due to disfigurement is a source of stress after burns and it is an important predictor of long-term psychosocial functioning (51). There are several studies pointing to the role of body image in adjustment to disfigurement in adult burn patients and that a newly fragile body strongly affects adaptation (51-54). Furthermore, it is shown to be a strong predictor of depression one year after injury (55). Identified predictors of increased body image dissatisfaction are female gender (51, 55), focusing attention on physical appearance (56) and having extensive burns (53). Burn severity is related to body esteem and attributions of others (50) and social acceptance and emotional variables have been found to have more significance for the body esteem of the burn patients than the severity and localization of the scars (56). There are also indications that visible scarring (e.g. face, hands) may lead to greater distress, especially in the interaction with non-family members (50). Alternatively, there is evidence that people with visible burn scars are forced to face the reactions of others and this may teach them how to effectively cope with these reactions (57). Disfigurement may also play a role as a reminder of the trauma and, subsequently, might maintain stress (58). People with disfigurement after burns will go through an initial development period in which body image will worsen over time and they will eventually develop the social skill necessary to cope with experiences of stigmatization (57). Precisely how long this period of adjustment will take is not reported in the

literature. However, many patients demonstrate good social and emotional functioning despite having a disfigurement after burns and appear able to cope with being physically different from others.

## **Posttraumatic stress disorder**

Posttraumatic stress disorder (PTSD) is categorised among the anxiety disorders, but it differs from other disorders because there must have been prior exposure to a traumatic event with a personal reaction of intensive fear, helplessness or horror that followed (58, 59). The central symptomatic criterion is that the traumatic event is experienced in an embarrassing and painful way. Re-experiences may be carried into the present in the form of intrusive thoughts or dreams and it is common to relive the horror that was associated with the events. Patients can feel as though they are experiencing the traumatic situation again; this phenomenon is called a 'flashback' (*intrusion*) and is often described as the essential feature of PTSD, although it can decrease over time. The syndrome also includes the condition of being in a constant state of alarm. The person is alert and tense, has a nervous excitability and experiences difficulty falling asleep, and is unable to concentrate (*hyperarousal*). Avoidant behavior can be understood as an adaptation to a situation where emotions of disaster are constantly at risk of emerging and may lead to fatigue resulting from the constant tension (*avoidance*). In addition, these symptoms must produce considerable subjective distress and impact on daily life for at least one month (59).

Many other reactions can follow potentially traumatic events, such as depression, chronic pain, substance abuse and increased risk of suicide, but these conditions can exist with or without simultaneous PTSD (59). A comprehensive review of the literature (58) reports that PTSD occurs in 20-45% of burn patients, 1-24 months post-trauma, but far more show signs of PTSD without meeting all of the criteria for this diagnosis. It seems that the intensity of symptoms decrease over time and their frequency became lower, although the symptoms were still present. Evidence exists to demonstrate that the pre-injury characteristics, such as psychiatric disorder and personality traits, are of importance for the development of PTSD in patients with burn injuries. Peri-traumatic characteristics such as avoidant symptom, dissociation and anxiety experienced during trauma may also predispose the development of PTSD. Female gender, especially when visible disfigurement is present, is particularly associated with development of PTSD. Coping styles such as emotion-focused coping and avoidant coping were both associated with PTSD symptoms as well as low levels of social support and high levels of neuroticism. Finally, sleep disturbance, anxiety related to pain and body image dissatisfaction (especially facial and hand injuries) all contribute to the development of PTSD (58).

## **Coping**

The term 'coping' relates to theories about the ability of people to adapt to internal and external stress and, by extension, to the health of the individual. According to Lazarus, (60) coping refers to "ongoing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the

resources of the person.” Coping is a process in time that is influenced by both personal and situational factors and should not be viewed as a stable personality trait, but instead as something mutable. For most people, coping entails successfully dealing with problems. In psychological contexts, coping is neither positive nor negative. In the literature, coping refers to various methods of managing a situation, and the choice of strategy may have either a positive or negative impact on the person’s adaptation (60).

According to Lazarus (60), coping has two primary functions: in part to resolve problems that cause stress, and in part to regulate emotions. The choice of coping strategy is preceded by two psychological processes (60): 1) an assessment of the risks associated with the specific situation, and 2) the individual’s ability to understand the situation, identify choices and determine what can be done. Both of these processes are influenced by individual character traits and external demands. This model includes appraisal of the situation, assessing the importance and activation of available resources, followed by the implementation of coping strategies, evaluation of the outcome and reappraisal (60). Emotion can be seen as the mediator in the coping process, causing the progression of coping to be filtered through the emotional reactions involved (61).

Coping strategies can be divided into *problem-focused coping* that involves an effort to solve a stressful situation through action, and *emotion-focused coping*, aimed at efforts to change the personal assessment and valuation of the situation (62).

Maladaptive coping strategies that lead to the person failing to solve their problems generate further anxiety, depression, anger and mental disorders, which, in turn, create new problems (62). Conversely, when individuals are able to control the situation by using problem-solving strategies, this instead regulates emotions within a stressful situation that is difficult to change (*emotion-focused coping*) (62).

Coping strategies play an important part in psychosocial adaptation to the burn injury. In response to a stressful situation, an individual often uses a variety of coping strategies (62). The coping strategies can be divided into separate factors which are quite similar, although these are given different labels by different authors (63).

*Avoidant coping* includes behaviors such as daydreaming, wishful thinking, the use of alcohol/drugs, and avoidance of people and activities (63). Avoidance is a maladaptive coping strategy which is strongly associated with depressive symptoms (64), level of hopelessness (65), overall poorer health, and less ability to return to work (66).

*Emotional support* is about the seeking of social contact and comfort and talking about the problems (63), and is acknowledged to be the most beneficial strategy for increasing the reported health of the patient (63) and leads to less severe depressive symptoms after burns (64). Seeking practical help and advice (*instrumental action*) is another form of support and an effective means of problem solving (63). Instrumental action is not related to positive outcomes, but instead to psychosocial difficulties and problems returning to work after burn injuries (63). *Revaluation/adjustment* includes implementing concrete changes in lifestyle, cognitively processing the accident (66), redefining life (63) and exercising meaning (67). This coping strategy has been shown to be negatively related to simple functional abilities (66), more emotional distress (67) and the use of this coping strategy is also related to the extent of the physical injury.

*Optimism/problem solving* is a confrontational coping style, and is characterised by being active and expending effort to make things work, noticing positive things and having an optimistic view of the future (66). Optimism has generally been shown to be a predictor for less severe depressive symptoms in follow-up, to affect health positively and to help patients to adapt to burn injury (63, 67). More optimistic attitudes and beliefs can, in turn, positively influence patients' compliance with medical procedures and can be indirectly connected with health outcomes (64).

*Self-control* reflects an effort to restrain emotional expression and it is negatively correlated with burn-specific health in body image and ability to work (66), and has also been found to result in an increased incidence of posttraumatic stress disorder (PTSD) (68). Choice of coping strategy does not differ between men and women, nor is it related to the size or location of the burn (65). Common strategies for dealing with pain and stress related to burn injuries include self-distraction, avoidance/denial (69) and wishful thinking (63, 67, 70).

The role of personality and coping in adjustment and the development of post-trauma symptoms shows that neuroticism accounted for most of the variance in PTSD (71), and this relationship was mediated by Avoidant coping (64). Resources such as social support can lead to remarkable resilience on the patient's part when confronted with situations of severe physical injury and substantial psychological distress (64). The results from various studies on coping and health are conflicting, often because views on the definition of coping and coping strategies differ, the studies focus on different phases of trauma recovery, and the circumstances of the selection group may affect choice of strategy. Even if coping is not viewed as adaptive in itself, some strategies are generally considered to be adaptive or maladaptive, although this division does not adequately explain differences in adaptation because it does not take into account the elements of time or process (61).

There are also a number of patients who experience burn trauma with no apparent existential crisis or difficulties in coping. Individuals cope differently with disability and there are no orderly stages of adaptation following trauma (45). In this thesis, coping is viewed as a process and the strategy choices made by burn patients may vary. Recovery after treatment is in itself an evolutionary process, which may lead to a shift in strategies over time.

## **Adaptation to life after burn**

Adjustment is a behavioral process of balancing conflicting needs, or needs against obstacles in the environment, which help people to adapt to new lifestyles and situations. Coping, which always involves some sort of stress, is the way in which people manage stressful life events, while adaptation is a broader concept that includes the element of routine, even automatic ones, and models of managing living alone (60). The terms 'adjustment' and 'adaptation' are used interchangeably in the literature without any defined difference between them. There is no accepted meaning of what constitutes adaptation after burns and how that adaptation proceeds.

A review of the literature in the field of psychopathology and psychological problems after burns show that the adjustment process is affected by factors that pertain to accident and injury characteristics, demographics, and pre-injury variables. Other important factors contributing to differences in adjustment after burn injury are coping style, how to approach a problem, social support and personality traits (58).

The relationship between personality type and coping strategies has a major impact on the adjustment to changes after burn injury. Disparity in the literature highlights the complexity and heterogeneity of burn patients as a group that makes it difficult to predict adjustment outcomes and find the conception for adaptation as a process. There are several mediating variables, such as low social support, emotion and avoidant coping styles, and personality traits as neuroticism that can negatively affect adjustment (58) and make the process of adaptation even more complex.

The first year after discharge has been identified as the most challenging period for the patient, with most adjustment issues for the burn injury remitting after this time. During this period a patient slowly regains a sense of competence and the practical limitations of a burn injury (limited range of motion, skin problems, and adjustment to disfigurement) are most salient. Over this period of time, patients struggle with secondary stress reactions, vivid memories of the accident and care, and often experience changes in family and occupational roles (7, 45). Regarding social adjustment, some evidence suggests that patients with family increase their interaction with the family, while those who live alone become more isolated post-injury. Most patients (66%) are able to return to work following their burn care within the first two years after experiencing the trauma (72), but many will still need to change their working conditions in order to cope with their new physical limitations. There is no evidence to support any change in marital status post-injury. Sex life is affected more often in women, due to both dysfunction and altered body image (7).

Despite the trauma, most burn patients adapt well to life after burn injury. Many people who experience a burn injury have difficulty adjusting and coping initially, but through time such traumatic reactions usually improve. In some cases, however, the symptoms can get worse and last for months or even years. Adjustment disorder occurs when there is an inability to make a normal adjustment to some need or stress in the environment and this can lead to stress overload.

## OVERALL AND SPECIFIC AIMS

The purpose of this thesis was to investigate the patient's experience during burn care and in the follow up with focus on pain, body image, stress and coping and explore adaptation to life after burn injury.

The thesis comprises four papers with the following specific aims:

**Paper I:** To describe burn patients' experiences and memories of pain during and after burn injury to acquire a deeper understanding of patients' issues of importance when providing care during and after burn injury.

**Paper II:** To explore burn patients' experiences of adapting to life after burns to acquire a deeper understanding of the most important issues for the patients when providing care during and after a burn injury.

**Paper III:** To culturally adapt and validate the Satisfaction with Appearance Scale into Swedish to be used in the context of burn care.

**Paper IV:** To investigate the presence of posttraumatic stress disorder, body image dissatisfaction, and coping strategies used three and six months after hospital discharge for early identification of patients in need of support during rehabilitation.

## **MATERIAL AND METHODS**

### **DESIGN**

To explain and understand a phenomenon, various research questions are asked and to properly answer them requires the application of a variety of methods. Because the purpose of this thesis was to shed light on the patient's experience from various angles, different methodologies were used for each of the individual studies. Papers I and II used a qualitative approach to explore and create meaning and understanding of the subjective experience of a burn. Paper III used a mixed-method approach where a qualitative exploration of the patient experience was completed before using quantitative data to describe the research topic. Study IV has a quantitative approach in order to further classify data, make connections and predict and explain the outcomes of the previous papers (73). An overview of the papers is shown in Table II.

Table II. Overview of the study design, sample, data collection and analysis.

Paper	Focus	Design	Sample <sup>1</sup>	Data collection	Instruments	Analysis
I	Describe patients' memories and experience of pain and coping during burn care	Qualitative Descriptive	n= 12 > 18 years of age LOS <sup>2</sup> > 7 days	Semi-structured Interview	Interview guide	Qualitative data analysis inspired by Kvale
II	Describe Patients' experiences of adaptation to life after discharge from the hospital	Qualitative Descriptive	n= 12 > 18 years of age LOS <sup>2</sup> > 7 days	Semi-structured Interview	Interview guide	Qualitative data analysis inspired by Kvale
III	Validation of Satisfaction with Appearance Scale in Swedish-speaking burn population	Mixed-methods	Pre-test n=13 ≥ 18 years of age  Testing of SWAP-Swe  n= 90 ≥18 and ≤ 75 of age	Translation and back translation  Pre-test interview  Questionnaires	<u>SWAP</u> original version  Focus Group discussion Individual interviews  <u>SWAP-Swe</u> Swedish version of Satisfaction With Appearance Scale	Qualitative data; transcribed text and field notes  Cronbach's alpha A principal components analysis (Varimax rotation) Spearman's rank correlation coefficient Mann-Whitney <i>U</i> test
IV	To investigate the presence of stressors and coping strategies in early follow-up	Quantitative descriptive validation, reliability study	n=52 in three month follow up  n=32 in six month follow up  > 18 years of age  LOS <sup>2</sup> > 24 hours	Clinical assessments 3 and 6 months after discharge  Questionnaires 3 month follow-up       Questionnaires 6 month follow-up	Clinical protocol    <u>IES-R</u> Impact of Event Scale-Revised  <u>SWAP-Swe</u>  <u>CBQ</u> Coping with Burns Questionnaire  <u>IES-R</u>	Mann-Whitney <i>U</i> test Wilcoxon signed-rank test       $\chi^2$ test Wilcoxon signed-rank test Spearman's rank correlation coefficient Mann-Whitney <i>U</i> test

<sup>1</sup> All the informants and participants in the studies are former burn patients

<sup>2</sup> LOS- length of stay in the hospital



## **PATIENT SELECTION**

The studies were conducted at the Karolinska University Hospital, Department of Reconstructive Plastic Surgery.

### **Patient selection criteria for papers I-IV**

Patients were strategically selected from burn patients treated at the Burn Unit between August 2005 and Feb 2007 (Papers I and II). Inclusion criteria were: aged 18 years or over, a length of hospital stay greater than 7 days, and to possess adequate communication skills for interview participation. Patients on a ventilator were excluded from the study to avoid the confounding effects of medications on memory. Also excluded were patients with mental illness, underlying disease with chronic pain and patients with substance abuse problems.

In paper III, the informants in the pre-testing phase consisted of burn patients who were 18 years of age or older, proficient in the Swedish language and possessing sufficient cognitive and communicative abilities to participate in the interview. Study informants included those burn patients between the ages of 18 and 75 years and who were proficient in the Swedish language. The informants were recruited from patients who had been hospitalised for burn injuries between 1<sup>st</sup> January 2010 and 31<sup>st</sup> July 2012.

In paper IV, consecutive burn patients in the Stockholm area admitted to the Karolinska University Hospital or other university hospitals between February 2011 and September 2012 were invited to participate in the follow-up study if they were: 18 years of age or older, Swedish-speaking, without documented mental illness or dementia, and had a length of stay in the inpatient burn care of more than one day.

## **DATA COLLECTION, PARTICIPANTS AND PROCEDURES**

### **Papers I and II**

Purposive sampling was used to select the informants. This included gender, age, and social background. An information letter about the study was first sent to eligible patients. Patients were then contacted by telephone 2-3 weeks later, and informed consent was obtained. A total of 104 patients were treated at the Burn Unit during the data collection period; among these, 31 patients met the inclusion criteria.

Ultimately, informant selection for both studies was identical and consisted of 12 adult informants; 8 men and 4 women. Seven of the patients were injured by fire/flames, two were scalded by hot water and three had come into contact with hot objects. An overview of participants in papers I-IV is represented in table III.

## Paper III

The method for the translation procedure and validation of the translated tool consisted of the following steps: 1) Translation of the SWAP questionnaire into Swedish and back-translation; 2) first committee review of translated text; 3) pre-testing of face validity of the questionnaire; and 4) analysis and second committee review. The last phase involved testing the questionnaire for validity and reliability in a population of burn survivors. Information about the study and a letter for informed consent were sent by mail to all respondents.

For the pre-testing phase, the informants were selected in consultation with the burn surgeon and the contact nurse who cared for patients at the outpatient plastic surgery clinic. Pre-test invitation to participate was sent to 22 patients; 14 of these were willing to participate in the study. Out of these, three participated in a focus group discussion and ten participated in individual interviews (9 women and 4 men). One patient cancelled their interview.

For testing the validity and reliability of the SWAP-Swe questionnaire, the translated tool was sent by mail to 163 patients who met the inclusion criteria for the study. After one month a reminder letter was sent to those who had not responded, and finally, 90 respondents returned the completed questionnaire. Burn-specific and socio-demographic variables such as data about the injury (burn size, injury severity, length of hospital stay, operation, time since burn injury), age and gender were collected from the patients' medical records. Analysis of non-responses was not made in this study.

## Paper IV

Patients were invited to attend a follow-up visit at the outpatients' clinic three and six months after discharge from the hospital. Information about the study, an invitation to take part in the study and a copy of the questionnaire were sent by mail to patients who met the inclusion criteria. Patients were asked to bring the completed questionnaires to the visit. Patients also had the opportunity to ask questions and complete the questionnaires during the visit, if any questions had arisen related to the questionnaires at home. Within the study period, 73 patients fulfilled the criteria to participate in the study. Of these, 52 participated at the three-month follow-up and 32 at the six-month follow up. Non-respondents consisted of 21 patients. There were no significant differences between the respondents and non-respondents with respect to age, gender, total TBSA burned, extent of full-thickness injuries TBSA- FT, severity of the injury, type of burns, surgery and length of stay. However, the presence of visible scars (face and neck) was significantly higher in the group that responded; 52% versus 9.5% ( $p < 0.001$ ).

At the three-month follow-up, assessment included the following questionnaires: Impact of Event Scale-Revised (IES-R), Swedish version of Satisfaction with Appearance Scale (SWAP-Swe), and the Coping with Burns Questionnaire (CBQ).

At the six-month follow-up, assessment included only the IES-R. The clinical protocol during the visit was the same at both follow-up visits.

Data about the patients' injury characteristics, age and gender were assembled from their medical records. Burn severity score, according to the Swedish National Board of Health (21), and Tobiasen's Abbreviated Burn Severity Index score (ABSI) (20) were confirmed by an experienced plastic surgeon. The total body surface area (TBSA %), the extent of full thickness burns (TBSA-FT %) and co-morbidity conditions that influence the severity of burns were included in the evaluation.

Table III. Overview of participants in papers I-IV

	Paper I +II	Paper III		Paper IV	
		Pre-test	Validation		
Sample, eligible/included	13	22	163	73	
Investigate	12	13	90	52 <sup>1</sup>	32 <sup>2</sup>
Gender, male/female	8/4	4/9	48/42	29/23	
Age, years, mean (SD)	49.6 (15.6)	45 (11.4)	44.7 (16.6)	41.8 (17)	
TBSA (%), mean (SD)	10.6 (10.2)	32 (21.1)	7.7 (8.7)	8.9 (8.7)	
LOS, days, mean (SD)	16.4 (11.4)	76.5 (66.6)	13.5 (19.9)	14.3 (18.2)	
Full thickness burns, number (%)	7 (58)	11 (85)	49 (54)	28 (54)	
Surgery during burn care, number (%)	8 (66)	10 (77)	50 (56)	29 (56)	
Visible scares (face/neck), number (%)	4 (25)	6 (46)	38 (42)	27 (52)	
Burn Severity <sup>3</sup> number of patients (%)					
Minor	2 (17)	2 (15)	42 (47)	23 (44)	
Moderate	7 (58)	2 (15)	38 (42)	20 (39)	
Severe	3 (25)	9 (69)	10 (11)	9 (17)	

<sup>1</sup> At three-month follow-up

<sup>2</sup> At six-month follow-up

<sup>3</sup> Burn severity according to Swedish National Board of Health

## Interviews (Papers I and II)

The informants decided where the interview would be conducted, either in a private room at the hospital or in the interviewee's home. The first author (OD) conducted all of the interviews, took the field notes, and performed the interview transcriptions. Interviews were conducted 6-12 months (mean 7 months) after discharge from the Burn Unit and the informants were interviewed on one occasion.

The interviews began by the interviewer clarifying the purpose of the interview, and reiterating that informants could terminate the interview at any time, which was also made clear in the letter of information. A semi-structured interview guide was prepared as a basis for the interview, consisting of topics covering areas of interest linked to the main aim of the study. The interview was initiated with an open question where the informants were asked to narrate their memories of being injured in an accident and cared for in the hospital, their memories of pain, and how they felt after coming home.

Any probing questions were based on the details given in the spontaneous answers to the initial question. Interview length varied from 60 to 90 minutes. Interviews were carried out in Swedish, audio-recorded and transcribed verbatim.

### **Pre-test (Paper III)**

Pre-testing of the translation of the SWAP questionnaire was carried out in two steps. The first step was a focus group discussion with three patients, carried out in a private room at the hospital. One of the researchers (YW) led the discussion. In the second step, individual interviews were conducted with ten patients in the hospital by the same person (OD). The respondents were asked to go through SWAP-Swe and encouraged to verbalise their thoughts when responding to the items. The interviewer asked respondents to clarify their opinions about the questionnaire's usability, its items' relevance to the context, and their overall impression of completing the questionnaire. Any items that had caused problems in comprehension or interpretation were discussed. All interviews were audio-recorded and transcribed verbatim and a synthesis of the text and the field notes were merged for the purposes of analysis.

### **Clinical follow-up and assessment of the patients (Paper IV)**

Follow-up care was based on the existing multidisciplinary approach. During the follow-up visit at three and six months after discharge, the plastic surgeon focused on symptoms and problems related to the burn injury, for example: evaluation of the healing of wounds, control of scar tissue, pruritus, pain, functionality and corresponding medical conditions. As a complement to the regular follow-up visits, an intervention from the burn nurse focused on lifestyle issues, symptom experience and the patient's ability to perform self-care, for example, wound care.

For the nurse follow-up, a standardised clinical protocol was prepared for systematic assessment of symptoms and problems. Patients also had the opportunity to ask questions and discuss any possible problems or questions related to the burn. The patients could also contact the burn nurse by phone when necessary.

### **Questionnaires (Papers III and IV)**

#### *Impact of Event Scale-Revised (IES-R)*

The Swedish version of the Impact of Event Scale-Revised (IES-R) was used to assess symptoms of PTSD. IES-R has recently been validated by Sveen *et al.* 2010 (74) to be a sensitive tool for the discovery of PTSD in burn patients and to have effective properties as a screening tool for follow-up after burns. The questionnaire contains 22 items which are divided into three subscales: Intrusion (8 items), Avoidance (8 items), and Hyperarousal (6 items). The items in the IES-R are rated as follows: 0 ("not at all"), 1 ("rarely"), 3 ("sometimes"), and 5 ("often"), where 0 means no symptoms and a

score of 5 is equal to a high frequency of symptoms. Total scores of IES-R  $\geq 40$  was set as a criterion for the indication of the risk for PTSD, based on published cutoff values (74).

#### *The Satisfaction with Appearance Scale (SWAP-Swe)*

The Satisfaction with Appearance Scale (SWAP) is designed to measure the subjective satisfaction with appearance and the social-behavioral impact of burn scars (75). The SWAP includes four domains (Dissatisfaction with Facial Features, Dissatisfaction with Body Appearance, Social Discomfort, and Perceived Social Impact). The questionnaire includes 14-items and the patients assess on a scale from one (strong disagreement) to seven (strong agreement) how well each item agrees with their perception of appearance. A total score (min 0, max 84) is obtained by summing up the scores for each item and a high value indicates a higher degree of body image dissatisfaction. Good internal consistency has been reported for the SWAP total score for burn patients (Cronbach's  $\alpha=.87$ ) (75).

The original SWAP was culturally adapted and validated to a Swedish-speaking burn population in paper III. The Swedish version of the Satisfaction with Appearance Scale (SWAP-Swe) was then used in paper IV.

#### *Coping with Burns Questionnaire (CBQ)*

The Coping with Burns Questionnaire (CBQ) is designed to measure coping among burn patients after their discharge from hospital (66). CBQ contains questions related to perceived problems after a burn and how to act, think and feel in difficult situations (66). The CBQ consists of 33 items on the six dimensions of coping: Revaluation/adjustment, Avoidance, Emotional support, Optimism/problem solving, Self-control and Instrumental action (66). Responses were recorded on a four-point scale from 1-4 (1: does not apply/not used, 2: used somewhat, 3: used quite a bit, and 4: used a great deal).

## **DATA ANALYSIS**

### **Papers I and II**

In papers I and II, the aim was to understand the subjective experience of the burn injury based on patient narratives. The interviews were analysed using a method inspired by Kvale (76) to structure, clarify and develop new meaning. The analysis is inspired by phenomenology, which focuses on understanding the context of the lifeworld of the study subjects and developing meaning from their experiences (76).

Papers I and II analysed texts from interviews simultaneously with data collection; the text was analysed in three steps: The first step was *condensation of the text*, in which

the transcribed text is first read several times in its entirety to gain familiarity and understanding of context. The text was then divided into short meaningful units in accordance with the purpose of this study. This step involves condensing the interviewees' statements into shorter formulations and restating the main meaning in a few words (76). The next step involved the *categorization of meaningful units* where the text is reread and meaningful units are organised in accordance with the purpose of the study. Meaningful units were systematically structured around a statement (76), and then classified under common subthemes and main themes. In the first and second step of the analysis, we adhered to the text as closely as possible; no changes were made to the original text and no interpretation was undertaken. For this part, we toggled between the entire text and its components to achieve both proximity and distance to the text. For the final step, a *cohesive narrative* was derived from the entire interview text based on an *in-depth, theoretical interpretation* from which the essentials were abstracted. The obvious elements of the text were interpreted to identify context and patterns in order to find new meaning in the text and themes. To increase the rigour of the analysis, the interview texts were reread on several occasions and, through discussion, the subthemes and main themes describing the obvious and latent content of the text were identified. The author and her principal advisor discussed text units and categories throughout the analysis until consensus was reached. Quotations were chosen from the interviews to illustrate the results, and they have been de-identified to ensure that the anonymity of informants has been maintained.

### **Paper III**

A mixed-methods approach was used in the study, and data were collected and analysed at different stages of the study. The committee review from the translation of the SWAP questionnaire from English to Swedish and from back-translation was completed to make certain that the translation was fully comprehensible in a Swedish context. Qualitative data were collected from pre-testing interviews and a synthesis of interview text and the field notes were analysed by the committee, which consisted of three senior nurses and two plastic surgeons. The committee analysed and evaluated the content validity of the SWAP-Swe from the interviews. The data were analysed item by item and verbal comments on the items were summarised. Furthermore, any problems identified were categorised in two categories; difficulties related to wording, and difficulties related to other causes, such as understanding the context or content of the item. Finally, the difficulties and comments noted from the pre-testing stages were quantified to get an overview of how frequently the items were commented on. Quantitative data were collected from the questionnaire (SWAP-Swe) and analysed by statistical analyses, as described below, to assess reliability and construct validity.

### **Statistical analyses papers III and IV**

Data were analysed using SPSS version 20.0 for Windows in papers III and IV. Demographic data were compared with *t*-test and  $\chi^2$  tests and descriptive analyses were

used for all variables. In paper III, internal consistency was examined by using Cronbach's alpha for each domain and the total score of the scale. A principal components analysis with Varimax rotation was used to report the factorial structure of the SWAP-Swe. Correlations between background variables and SWAP were assessed by Spearman's rho and differences in patient characteristic and SWAP-scores were performed by Mann-Whitney test. The non-parametric test was used as SWAP items and subscales are of the ordinal data type.

In paper IV, group comparisons for the responders and non-responders were studied by means of Student's independent *t*-test for two groups. The Wilcoxon signed-rank test was used to analyse changes in IES-R scores over time. When comparing groups (e.g. risk/non risk for PTSD), the  $\chi^2$  test was used when comparing categorical variables, and the Mann-Whitney U test was performed when comparing variables of ordinal type or data diverged from normally distribution. Correlations between background variables and SWAP-Swe as well as CBQ were assessed by Spearman's rho.

## **ETHICAL CONSIDERATIONS**

Ethical considerations based on the Ethical Guidelines for Nursing Research in the Nordic Countries (77) and according to the principles of the Helsinki Declaration, 2004 (78) were observed in each of the studies. Central to these guidelines are respect for human dignity, an affirmation of human rights (free will, integrity and confidentiality) and basic human autonomy. Ethical reviews were carried out for all of the papers. Studies I and II were approved by the Research Ethics Committee Nord, Karolinska University Hospital Ref. no.: 02-082. The Regional Ethical Review Board of Stockholm approved studies III and IV (Dnr: 2011/342-31).

According to the principle of autonomy, all patients were informed about the study by a letter describing the study background and purpose, which stated that all research materials would be made anonymous and kept confidential. They were informed that study participation was voluntary and would not affect their future care, and that they could request termination of the study at any time, without providing any reason.

Papers I and II involve research on people who may find themselves in situations where they may feel vulnerable or exposed. As prerequisites of autonomy, the research must, as far as possible, predict any negative consequences and how these may be countered. The PhD candidate who participated in data collection was well aware of this situation and was careful during the research process to show respect and consideration for the individual. Since it is difficult to determine how deeply and for how long a burn injury affects the individual, ethical considerations in choosing the most appropriate time to interview trauma victims are complicated. Ultimately, one must rely on these patients to best determine when and how they wish to talk about their experiences. Interviews were conducted 6-12 months after patients had been discharged from the Burn Unit, which means that events and experiences may still have been fresh in their minds and may have affected the informants to varying degrees. A social worker with burn patient experience was contacted before the study began and it was determined that the interviewer could refer the patient to her if necessary and/or if the patient so wished.

In paper III, respondents who were dissatisfied with disfigurement and who wished to get in contact with a plastic surgeon were given the possibility to do that. In the follow-up study, paper IV, respondents who were identified as being at risk of developing PTSD at the three-month follow-up interview were referred for further treatment during the study.

## **PRE-UNDERSTANDING**

The researcher's own understanding of the situation affects the internal validity of a qualitative approach. The knowledge and experience of the researcher in a particular field may be both an advantage and a disadvantage to the quality of the research. Pre-understanding may bias the researcher, in which case some knowledge may be overlooked, or certain values may even be imposed on the work, which could affect the outcomes of the study. However, personal experience is also important to achieve deeper understanding. Knowledge that accompanies a good pre-understanding may prove highly important to the satisfactory creation of a holistic picture of the situation. In part, pre-understanding entails an understanding of conceptual knowledge (44) (such as pain) and in part, contextual knowledge (what it means to be in pain).

Because of my extensive experience in burn care nursing, I am familiar with that context. I am acquainted with the various phases of burn care and have some understanding of how patients experience care. One focus of this work is pain, for which I already have a conceptual understanding because I have personally studied pain and pain physiology. My attitude, however, is that additional knowledge is required to advance conceptual understanding of this phenomenon. Another focus in this thesis has been coping and adaptation to life after burns. In that field I have less experience in the theoretical manner and my own understanding is based on observations, reflections and nursing with different patients in burn care. This background may perhaps be an asset for interaction and dialogue during patient interviews, and for the interpretive process concerning the words and contexts of patient narratives.



## RESULTS

### MEMORIES OF PAIN AFTER BURN INJURY – THE PATIENT'S EXPERIENCE (PAPER I)

The purpose of this study was to describe patients' experiences and memories of pain during burn care to acquire deeper understanding of how patients cope with these experiences.

The reading of the interview texts showed that the accident itself was a transformational event for patients and that the informants remembered their entire hospital stay very well. The informants passionately relayed their experiences and memories, and the narratives assumed a chronological order from the time of injury until they returned home. During the structural analysis, four main themes (with four sub-themes) were identified for pain and four main themes (with two subthemes) for coping:

- To *become aware of pain* and manage it using *pragmatic coping*, at the time of the accident.
- To *allow yourself to feel pain* and *allow someone to take care of you*, upon arrival at the hospital.
- *Different pain experiences* with subthemes of *discomfort during treatment* and *exhausting pain*, and managing this with *carrying the pain during hospitalization* in the Burn Unit.
- Living with a *fragile body surface* with the subtheme, *new perceptions* at home, and managing this by *gaining perspective* on the burn injury.

Results from each theme are presented as summary descriptions below.

#### Pain

Almost all informants felt severe pain immediately after the accident, and waiting for help was extremely difficult and experienced as being stressful. The pain was described as a burning, stabbing pain, a type of pain that none of the informants had previously experienced. The pain increased on the way to the hospital, and once in the emergency room, informants became aware of what had happened as the pain continued to intensify. The pain from the burn itself was related to the wounds and was present throughout the treatment period and causes much discomfort. Pain at rest affected the ability to move in bed and was described as burning and throbbing. The pain associated with dressing changes was described as the worst pain that informants had ever experienced. The pain was "horrible" when bandages had adhered to the wounds and reopened the wound surface on removal; sores and blisters that burst, bled and festered were experienced as "awful" and informants had a feeling of being

“unclean”. Showering in particular was perceived as painful, with feelings of burning and hypersensitivity to different water temperatures. After these treatments, informants experienced exhaustion and extreme weakness. Moving around and getting out of bed were painful and reactivated the pain; regaining control required time. Two of the informants had false memories of their hospital stay, such as staff trying to harm them by pulling barbed wire from their body and holding the patient down with force. Upon returning home the skin felt taut and the skin surface was hypersensitive to heat, cold and touch. The body surface was perceived as being tender with increased pain, burning and itching.

## **Coping**

At the accident scene, informants were occupied with extinguishing the fire and helping others, while trying to cool themselves. Some did not allow themselves to feel pain, but experienced an “out of body” state, as if the brain had not had time to comprehend that they were in pain. Once the informants had received care, they allowed themselves to feel pain; some described this as a collapse during which they partially lost their grip on reality. Informants said that it felt good to be cared for since they did not know how to care for themselves in this situation, a response which was experienced as being both confusing and shocking.

Generally, during the hospital stay, coping entailed trying to “endure” the pain, getting used to it, “biting the bullet” and not complaining. None of the informants expected the nursing staff to completely alleviate their pain and they understood that there was no short-cut to healing, except through the pain. Some informants tried to screen off the pain by blocking it and not “feeling” the injured part of the body.

Family and friends, and to some extent, healthcare staff, were described as providing both aid and comfort to distract from the pain. Visits from friends and family provided comfort, while serving as a link to life outside the hospital, and helping informants to look forward and feel encouraged to recover and manage more and more on their own.

Self-care was prominent and informants sometimes used this strategy to try to take charge of the situation. Striving continuously to mobilise themselves, to create new goals and to help with their own therapy was perceived positively by many. Gratitude for the care they received and an understanding of how badly things could have turned out helped them to view the hospital period as a limited period of time and made it easier to “endure”.

Some informants used denial to cope and struggled with feelings of aggression and despair that resulted in an inability to adapt to the situation, which was expressed by keeping family at a distance, and an unwillingness to ask for help, maintaining rigid self-control, enduring pain and using self-restraint. They also refused to participate in their own care and were unable to emotionally manage loss and trauma.

Once at home, informants suffered from fatigue and depression when faced with the demands of daily living. Some described experiences of flashbacks of the trauma and difficulties weaning themselves off pain medication and anxiety over regaining normal sleep. Pain and unpleasant experiences were still part of daily life. As time passed after the accident, with support from family and an understanding that the healing process is ongoing, most people found the situation to be manageable.

## ADAPTING TO LIFE AFTER BURN INJURY – REFLECTIONS ON CARE (PAPER II)

The purpose of this study was to explore the experiences of patients as they adjusted to post-injury life and to acquire deeper understanding of the most important issues for patients providing care during and after burn injury.

A summarizing interpretation of the interview text showed that informants depict post-injury life as a *struggle to live with the consequences of a burn*. This struggle consists of various ways of dealing with new circumstances in living with a fragile body surface, the limitations of carrying out daily tasks, unpleasant sensations in the body and continuous emotional processing of the trauma. The interpretation of this whole is based on three main themes: a fragile body surface, coping and reflections on burn care, as well as ten subthemes, as illustrated in table IV.

Table IV. Theme and subthemes identified about adaptation to life after burn injury.  
“Struggling with the consequences of the burn injury

Subtheme	Theme
Pain and new triggers Restriction of daily activities and being vulnerable Fatigue New relation to fire/water	Fragile body
Fighting and trying to be strong Perspectives- reflections on what happened	Coping
Pain treatment and lack of participation Consideration in care Lack of support and information Own participation for recovery	Burn care-reflection on care

### Fragile Body

The burned body was described as having become sensitive to new stimuli that triggered pain. Several informants described being overly sensitive to heat, cold, wind, touch, and certain clothing. Patients described the pain as being acute, coming and going for no apparent reason and eventually shifting into an itching phase. The new body was perceived as fragile and lacking durability for daily tasks. Several activities, such as showering, required careful planning so that help would be at hand to apply lotion to the skin afterwards in order to avoid irritation and itching. The injured areas felt plastic and unreal, with muscle weakness and limited ability to move. Increased sensitivity to solvents caused tingling in the hair roots of the skin, and problems with fine motor function of the fingers made it difficult to return to previous occupations.

Visible burn scarring was a problem, especially for two female informants. As a result of this problem, they felt no sense of freedom and spent less time in the company of others, especially in summer. Two informants had significant emotional problems; felt isolated, had difficulties maintaining a regular schedule and experienced sleeping problems. They did not trust themselves, nor their own ability to solve problems.

Five informants were overwhelmed by fatigue and their inability to participate in daily life. Despite an apparently good night's sleep, they experienced fatigue. They felt ambivalence to returning to work and assuming more responsibility, needing more time for rest and reflection. Several informants were uneasy in the presence of fire and hot water. Many refrained from lighting candles or a fireplace, since this created anxiety, and they were unsure how they would react to a sensation of heat.

## **Coping**

Coping and adapting to life after a burn injury is all about the constant effort to become accustomed to and accept the new life circumstances. The goal is to feel whole once again. Part of this strategy is to struggle and try to get used to the situation and even to try to forget – to view the burn injury as a long healing process, without any expectations that someone else can remove the suffering. Coping involved looking back and reflection on what really happened and how it has affected life while finding new perspectives and evaluating life. At the same time that patients are struggling to heal, they are also trying to preserve what is still normal to them, to manage their hygiene and strive to look healthy and attractive. Nine informants stated that close family provided important support during the adaptation process, including warmth and consideration in addition to assistance with practical matters. Already beginning during the hospital stay, friends and family served as a link between normal life and the informant's life in hospital and were also a strong motivating force for efforts to become well.

Looking to the past and distancing themselves from the accident is one adaptation strategy that provides perspective on how badly things could have been and how they actually are today. Several informants described how after barely surviving and being given a second chance, they no longer took life for granted. They described feeling calmer, showed more consideration for others and had a greater understanding of sick people afflicted with pain and suffering. Emotions such as being thankful for being able to manage on their own, taking greater advantage of life and the insight that others may be worse off, were all new to the informants. The burn injury was a reminder that life can take a drastic turn, how important it is not to become mired in trivial matters, but instead to try to form good relationships in the here and now. The family was viewed as being most important and something to be cherished.

## **Burn care – reflections on care**

In general, most informants were grateful for the kindness and warmth provided by the nursing staff and surprised that the care system worked so well. Informants perceived participation in care by family and friends as being positive. Informants described pain

management as something managed by nursing staff over which the informants had no influence. Pain management was generally effective, but once the medications began to wear off, terrible pain returned. Nevertheless, no one had any expectations that nursing staff could relieve pain completely. None of the informants became involved in their own pain management. They had little knowledge about the type of medication they received and they had not participated in any discussions about treatment choices. Individuals among the nursing staff were perceived to have varied skill levels and some were more generous with pain management than others.

The nursing staff showed consideration through their efforts to help informants find a more comfortable position in bed, by changing pain management strategy and by being vigilant for expressions of pain or discomfort during dressing changes. Few informants addressed support for handling various emotions. When nursing staff found the time to sit and talk for a while or touched patients (e.g., by holding hands) this was perceived as being very valuable and served as a distraction from the loneliness and pain. When nursing staff “cheered on” patients and informed them that they were making progress and doing well, informants perceived this as encouragement and confirmation that recovery was on track.

Several informants had no information about their care, wound and pain management or what further treatment was planned. They felt that they were left alone to imagine what would happen, and that some information was inconsistent and confusing. All informants lacked information about the dynamics of wound healing in particular. They perceived that all aspects of their care were self-evident to the nursing staff, but that this was not communicated to the informants. They also experienced a lack of support for their participation in their physical fitness regimen. These patients considered access to physical exercise to be as important as medications. Physical therapy visits were poorly planned and several patients felt that they were drowsy and tired during the visits and therefore unreceptive to information. The informants felt isolated and few had the opportunity to interact with nursing staff. Some felt they were left alone to process their loss and grief, which subsequently delayed the adaptation process at home. They described an inability to ask for help during their hospital stay, but later stated that they would have needed it. Social worker visits also failed to provide the support informants needed; they felt they would have been more receptive to such help later in their care or after discharge. Returning home caused insecurity and confusion and unfamiliar feelings arose. None of the informants had sought help for this and most processed the situation with the help of family and/or tried to forget.

Many informants showed the initiative to participate in and influence their own care. They found better, less painful ways to get out of bed, dress their own wounds and prepare themselves for various treatments. Several were surprised at how much they could do on their own, and some found that one way to manage the situation was to set personal goals with their physical exercise. As they felt physically stronger the need and desire to socialise with others grew. Encouragement and positive feedback from the nursing staff resulted in greater self-esteem among informants.

## **THE CULTURAL ADAPTATION AND VALIDATION OF A SWEDISH VERSION OF THE SATISFACTION WITH APPEARANCE SCALE (SWAP-SWE), (PAPER III)**

This study aimed to culturally adapt and validate the Satisfaction with Appearance Scale into Swedish to be used in the context of burn care.

*Translation and back-translation* of SWAP was made but two independent translations proved to be quite different from each other, and an internal review by the committee was necessary to achieve agreement between the source and target versions to assure suitable for use within burn care.

*Face-validity* was assessed by 13 former burn patients. The pre-test showed that some of the items in Swedish version were problematic to understand and for *semantic equivalence*, three words from the original questionnaire were changed by the committee during the pre-test.

Item 11, “I am satisfied with the appearance of my chest”, assesses the subjective appraisal of body image concerning the chest, but this was understood by all respondents as referring to the breasts. Consequently, the word was changed to the Swedish word for torso (“bål”). Item 12, “Changes in my appearance have interfered with my relationships”, is designed to assess social-behavioural components of body image, however, the respondents perceived this item as a statement that only changes in appearance could impair their relationship to other people, thus neglecting other dimensions of this experience. To improve understanding of this item, we choose instead the Swedish word for affect/influence (“påverka”) and thereby portray a more neutral nuance. These changes were necessary as there were no suitable corresponding Swedish words with equivalent meanings. Neither the former patients nor the review committee found any question that was not suitable in the current context due to experiential equivalence.

Clarifications in the instructions for the questionnaire were also made before the current version of the SWAP-Swe were tested for its psychometric properties in 90 former burn patients.

Descriptive statistics show that, generally, some items on SWAP-Swe have higher scores (greater dissatisfaction), for example, item 4 “satisfaction with overall appearance” and item 13 “feeling that burn is unattractive to others”, as illustrated in Figure 1.

SWAP-score

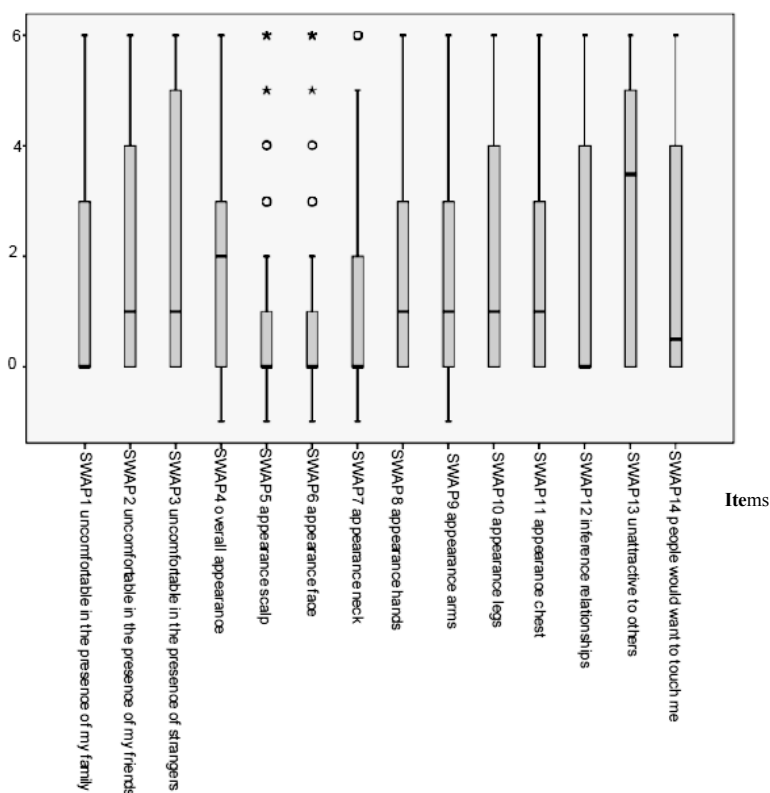


Figure 1. Descriptive statistic for the items in SWAP-Swe.

*Construct validity*, which refers to how the items in the questionnaire are related to the underlying phenomena, was evaluated by principal-components analysis. This analysis yielded three interpretable components, which together accounted for 68% of the variance. Component 1 was mostly related to items measuring social discomfort due to appearance (items 1, 2, 3) and perceived social impact (items 12, 13, 14). Component 2 was related to items measuring facial features (items 4, 5, 6, 7). Component 3 consisted of non-facial features (items 8, 9, 10, 11). These patterns correspond well to the subscales in the original SWAP and indicate good validity.

As a part of construct validity, the SWAP-Swe was correlated with same patients' characteristics. Greater body image dissatisfaction was found for **female gender**, for patients, who undergo **surgery during care** and patients with **moderate burns**.

A weak relationship was identified between body image dissatisfaction and scores relating to length of stay and extent of burns, TBSA.

The internal consistency as an aspect of reliability of the Swedish SWAP was examined by using Cronbach's alpha and exploring inter-item correlations. The Alpha coefficient was 0.89 indicating a high level of internal consistency in the Swedish SWAP. The mean inter-item correlation was 0.38 (0.32 in the original SWAP).

## **EARLY ASSESSMENT AND IDENTIFICATION FOR POSTTRAUMATIC STRESS DISORDER, SATISFACTION WITH APPEARANCE AND COPING IN PATIENTS WITH BURNS, (PAPER IV).**

This study aimed to investigate the presence of stressor and coping strategies and used three- and six-month follow-up for the early identification of patients in need of support during rehabilitation.

**Posttraumatic stress disorder (PTSD).** At the three-month follow-up, 30/52 (58%) of the respondents in this study met the criteria for risk of posttraumatic stress disorder (PTSD). The majority of these respondents had minor (n=11) or moderate (n=13) burns.

At the six-month follow-up, the risk was observed for 15/32 (47%) of the respondents. Thus, 32 respondents completed both three- and six-month follow-up questionnaires. Out of these, 15/17 respondents who had a risk for PTSD at three months still had total IES-R scores  $\geq 40$  at six months. The total IES-R scores and the three subscales had a tendency to decrease over time, but this was only significant for Intrusion ( $p > 0.001$ ).

The risk for PTSD was significantly related to factors such as

- Length of hospital stay
- Presence of surgery during hospitalization
- Experiences of pain
- Presence of nightmares
- Patients with greater body image dissatisfaction

Gender, the severity of the burn injury, and presence of visible scars did not significantly correlate with the risk for PTSD.

Respondents at risk of developing PTSD used more extensive maladaptive coping strategies (avoidance, self-control, instrument action and re-evaluation/adjustment).

Respondents identified as being at risk of PTSD were referred to a psychology clinic for further assessment and treatment if needed. It was confirmed in dialogue with the psychologist that the majority of these respondents suffered from PTSD or displayed evidence of having intense levels of subsyndromal PTSD and were in need of support.

**Satisfaction with appearance assesment by SWAP-Swe** showed that **women** and those respondents who underwent **surgery during burn care** reported higher degrees of dissatisfaction with appearance.



The aspects which also significantly correlated with body images were:

- Extent of burn injury (TBSA), especially with the subscale Body Appearance
- Presence of deep burns (TBSA-FT), especially with the subscales Facial Feature, Body Appearance and Social Impact

Dissatisfaction with appearance could potentially predict the risk for PTSD at the three-month follow up. The total SWAP-score was higher (median 34) for the respondents in the group at risk of PTSD when compared to (median 12) the group with no risk of PTSD ( $p < 0.001$ ), as illustrated in Figure 2.

When analysing the correlation between total SWAP-scores and IES-R scores on an individual level, the results were almost the same (correlations coefficient  $r = 0.627$ ,  $p < 0.001$ ) indicating a significant correlation between body image dissatisfaction and the risk of developing PTSD (see Figure 3).

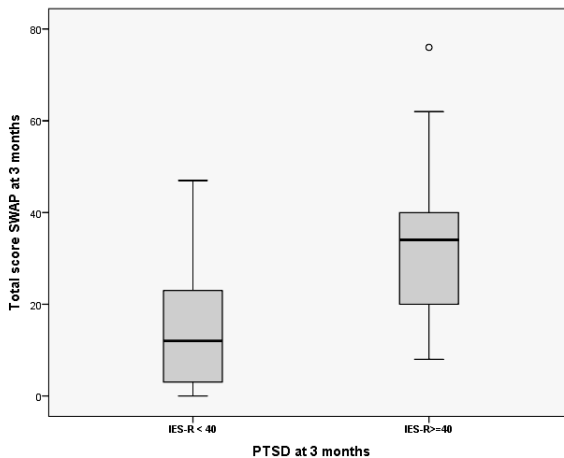


Figure 2. Correlation between PTSD and body image dissatisfaction at the three-month follow-up, for the group risk for PTSD and no-risk fort PTSD.

\* Statistically significant Mann-Whitney test.

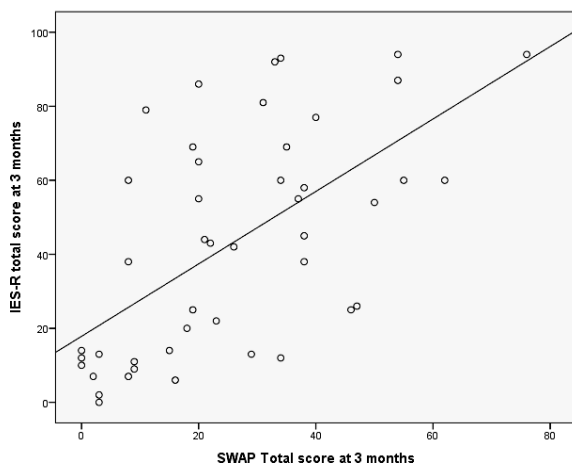


Figure 3. Correlation between risk for PTSD and body image dissatisfaction at the three-month follow up, visualizing individuals.

In general, the most commonly used **coping strategies** used by respondents at the three-month follow-up was optimism/problem solving, re-evaluation/adjustment and avoidance. No correlation was found between age and coping, but a significant correlation was found between gender and coping, showing that women used more re-evaluation/adjustment ( $p=0.008$ ) and avoidant coping ( $p=0.011$ ) than men. Subscales social discomfort and social impact on the SWAP-Swe correlated with all coping strategies, most with avoidance, without optimism/problem solving, indicating that respondents were making efforts to manage these aspects of their disfigurement.

Most respondents were able to take daily care of their burn scars by themselves. The follow-up by a specialised burn nurse includes the provision of support to the respondents with additional advice on skin care and the use of compression bandages for the prevention of scar formation. At the three-month follow-up the respondents were focused on burn healing, scars and physical training. Common problems related to burns mentioned by the respondents were that sleep disruption, itching and exhaustion interfered with daily routines such as physical exercise. Respondents experienced an impact on their quality of life and a fear of facing questions about the burn. Many respondents avoided situations with exposure to heat, for example, cooking, which led to less home-cooked meals and a change in eating habits.

The psychological support mostly consisted of advice and support related to visible burn scars and situations where people ask the respondent about the burn or are staring. The burn nurse helped the respondents by suggesting different ways to cope with social life through simple advice and also by presenting a program, Steps, which gives practical advice on how to interact with other people (79).

# **SUMMARY OF FINDINGS**

## **PAPER I**

All informants had clear memories of pain and experiencing pain throughout the treatment period and, for some, even when they returned home. Many daily care interventions were experienced as painful by informants and various wound treatments were perceived as the worst pain they had ever experienced.

In general, coping during hospitalization was characterised by efforts to “endure” the pain experience itself, to “get used to it” and “bite the bullet”. Friends and relatives play an important role in helping patients to endure difficult situations.

## **PAPER II**

Informants depict post-injury life as a struggle to live with the sequelae of a burn injury. This struggle involves various ways of dealing with new circumstances in a fragile body, with limitations to activities of daily living, new unpleasant body sensations and emotional processing of the trauma.

Informants readjust to life through reflection, by distancing themselves from the burn injury and by modifying their priorities when setting goals of feeling “whole” again.

Many areas for improvement are to be found in the burn care process, such as pain treatment and informing and involving informants in care to a higher extent, as well as providing support to informants for coping with emotional problems, not only during the hospital stay, but also during the immediate post-discharge period.

## **PAPER III:**

The Swedish version of the Satisfaction With Appearance Scale (SWAP-Swe) is a reliable and valid instrument for assessing body image dissatisfaction in a Swedish-speaking population of burn patients.

Higher body image dissatisfaction was found for female gender, for respondents with moderate burns and for respondents who undergo surgery during burn care.

## **PAPER IV:**

A significant amount of burn patients, even those with less extensive burns, are at risk of developing posttraumatic stress disorder three months after hospital discharge.

This risk is related to the length of hospital stay, surgery, pain, nightmares and greater body image dissatisfaction. Body image dissatisfaction could potentially predict the risk for PTSD at the three-month follow-up.

Female gender, a more extensive burn injury (TBSA), the presence of deep burns (TBSA-FT) and surgery during burn care all have correlations with body image dissatisfaction.

## DISCUSSION

The purpose of this thesis was to increase knowledge and understanding of the patient experience of stressors and adaptation to life after burn injury. The multiplicity of the research areas on which the individual papers are focused necessitated a variety of different scientific approaches to effectively explore the topic overall. Hopefully, the different approaches complemented each other to elucidate the overarching purpose of this work.

### General discussion of the findings

#### *Memories of pain – patients' experiences*

The results in our study show that burn patients have vivid memories of pain, even up to 12 months after returning home. Patients provide a multifaceted description of burn pain and many aspects of daily burn care are painful. Detailed descriptions of pain were given that fit well with the different types of pain described in the burn literature (31, 33), suggesting that pain during wound care and dressing changes were experienced as being the most excruciating and anxiety-provoking. After these treatments, respondents experienced exhaustion and extreme weakness.

Very few studies have assessed the experiences of burn patients using qualitative methods, but extreme physical pain has been described as being “excruciating” and “sticking pins in one” in a study conducted by Williams et al (80). In a study by Moi et al (54), similar experiences were found in interviews with burn patients, for example, experience of a new bodily awareness, where the body had been totally weakened while hospitalised and the patient was unable to move and manage daily activities, in Moi et al's study this was described as even being unable to lift a spoon. This finding was interesting; despite the fact that these descriptions were not clearly related to pain, they do refer to the complexities of these experiences of burn care. A study on patient satisfaction 2-4 years after burn injury (81) reported that a sense of powerlessness was the most common feeling recalled by the patients, but no further analysis of this phenomenon was provided.

In our study, upon returning home, informants described the body as being vulnerable in a new way; the skin felt taut and fragile, and the skin surface was hypersensitive to new triggers such as heat, cold and touch. The body surface was perceived to be tender with increased pain, burning and itching. A newly vulnerable body was also described in the study by Moi et al (54), where new bodily sensations, such as pain, itching, warmth, cold and tightness, were identified among burn patients about 13 months after the injury occurred (54). The descriptions in their study about friction against thin skin and knocking against sensitive skin causing smarting and pain supports our findings (54).

A literature review of evidence of memories of patients with burn injuries confirms that the majority of trauma patients have a clear recollection (e.g family members' visits, voices, pain) and/or delusional memories (e.g dreams, nightmares,

hallucinations, unreal experiences) after critical care (82). There is an association between delusional memories and length of ICU stay, sedative and analgesic medication, infections and high fever, ventilator support and renal failure (82), all conditions familiar to burn patients. In our study, two of the respondents had delusional memories of their hospital stay. These patients had, however, more extensive burns, leading to a relatively longer length of stay and more invasive treatment procedures. Furthermore, patients who were heavily sedated and were treated on a ventilator were excluded from our study and this might explain the few descriptions of delusional memories.

In our study, the unpleasant memories of pain and care procedures were strongly recollected. One reason for this result may be that pain in burns are one of the most intense and prolonged types of pain, and is strongly related to burn treatment (33). Time between the injury and the interview could affect memories, but previous studies have shown that at 12 months after being discharged the memories of emotions during care are extensive, detailed and strong and appear to be quite stable over time (82), even if the unpleasant emotions are less intense and prominent compared to those reported at 3 months after discharge (83). A multicenter study of memories after intensive care among trauma patients, 6-12 months post discharge, showed that the most common emotional memory during care was pain and this was reported by 70% of patients (84).

Episodic memory is a past-oriented memory system and it makes it possible for mental time travel through subjective time, from the present to past, thus allowing re-experience of past experiences (85). Stokes et al (86) studied the effect of burn injury on episodic memory (autobiographical memory) in adolescent burn patients and a matched control group. Burn patients were slower to recall memories connected to negative cue words, indicating that burn trauma increased latencies in retrieving episodic information, but burn patients produced significantly more extended memories than those in the control group. Burn events were also marked by greater intrusive memories than for the control group (86).

Descriptions of severe pain and major discomfort during burn care in our study, paper I, can be perceived as criticism of health care. At the interview, the patients were encouraged to share memories of pain and also what made the pain worse and what alleviated pain. Patients felt free to talk about experiences without any preconception of this being negative for the care. At the time of the study the Burn Unit had facilities to run both ICU and operating theater at the unit, and a multidisciplinary burn team with extensive experience in burn care. However, this is the first study as far as we know focusing on the patient's experiences of pain by using in-depth interviews. Although the number of patients is limited, other burn patients can probably recognise the result.

It is well known that pain after burns is something that many patients carry in their minds. The survey of Brown et al (87) shows that 18% of respondents still have burn-related pain, on average, 5.3 years after the burn injury and that pain was still affecting sleep, ability to work and mood (87). Respondents with persisting pain recalled significantly higher levels of pain during dressing changes (mean 7.40 in the Pain Intensity Scale 0-10) than patients with no pain. In a survey of Dauber et al (37), 96% of respondents reported the presence of pain during burn treatment, on average, 12 years after injury. The mean intensity and overall pain during burn treatment was rated at 4.4 (SD 1.0) on a scale of 0-5 and memories of the accident were associated with

making the pain worse (37). Dauber et al found also association between recalled acute pain episodes in the in- patient settings with persistent pain(37). Despite that measures of pain intensity were not assessed in our study, the narrative data show that pain during care can be distinguished and recalled in the first year following injury and that these memories can be stressful for the patient.

Informants on our study described pain management as something managed by nursing staff over which the respondents had no influence. Pain management was generally effective but patients had not had any expectation that the pain would be completely gone. Little is known about what influences patient satisfaction with regards to burn pain management. The first prospective study focusing on patient satisfaction outcomes with acute pain treatment (in the first 48 hours in the care) and perceived improvement in the early recovery period (3 month follow-up) (88), reported that satisfaction with acute pain treatment was predicted by age, with elderly patients reporting that they were more satisfied, treatment expectations, and current pain at the time of reporting satisfaction. Those with higher pain intensity at the follow-up time-point were less satisfied with their pain treatment and recovery (88). The current pain intensity was not assessed in our qualitative study (paper I) but almost all informants reported still experiencing burn-related pain and that may have affected their satisfaction of pain treatment.

Research provides us with a good understanding of the various types of burn pain and their characteristics, but it seems we have not come far enough with pain management to alleviate the type of pain and suffering that patients describe in our study.

Individuals among the nursing staff were perceived to have varied skill levels and some were more generous with pain management than others. Burn pain management is challenging for the nurses and it is easy to experience frustration over being confronted with the prospect of both relieving pain and causing pain through repeated wound treatments. Studies have noted that burn staff members failed to medicate patients adequately with opiates, despite education (29), and nursing staff usually underestimate patients' desire for analgesic therapy in the burn settings (35). Pain management in burn patients is difficult and it requires a burn nurse who is confident with both pharmacological pain treatment and psychological support to alleviate anxiety. Nurses who are inexperienced in burn care may feel uncomfortable prescribing and administering these higher-than-usual opiate doses, despite their appropriateness for the patient with burn injuries (29). The patient's experience of pain after a burn injury depends on many factors and the patient's needs change over the course of each day and in each phase of recovery and assessments taking into account this dynamic nature of burn pain are essential (46). It is important to note that some of the reasons for the patient's distress may have overlapped, for example, pain or discomfort at donor sites, and itching and wound care and it might be difficult for the patients to give a clear picture of which one of these symptoms is most salient at the time.

Nurses' exposure to patients' pain resulted in their own emotional exhaustion, distress and desensitisation to pain, which has implications for both the care of the patient and the nurses' well-being. Burn nurses are familiar with the feeling of not succeeding to relieve pain during wound treatments (89). Research of nursing in burn care shows that nurses have to build up a resilience to these emotions that will assist them to bounce

back and to cope in the face of adversity to sustain them through the challenges of burn care (89). Another factor contributing to inadequate pain management in burn patients is that many health care professionals view pain as a temporary problem. It is difficult to convince the health care professionals that, for the patients, experiencing such pain during their treatment may result in any long-term complications (35).

Beyond the pharmacological treatment of pain, the psychological response of patients is significantly important, as described in our study. When nurses showed consideration through their efforts to help respondents, such as helping the patient to find a more comfortable position in bed, being vigilant for expressions of pain or discomfort during dressing changes, or taking the time to sit and talk for a while or touch patients (e.g., by holding hands), this was perceived as being very valuable and served as a distraction from the loneliness and pain.

Pharmaceutical treatment options are numerous, yet insufficient to relieve burn pain by themselves. Many non-pharmacological pain relief methods (e.g., hypnosis, diversion, relaxation) may potentially complement treatment and need to be implemented in burn care. There is also a need to do more to prepare patients for hospital care and what might be entailed in their care plan. It is important for the health care staff to form an image of how the person behind the burn feels, and what resources (emotional and cognitive) the patient can call upon to manage and control their pain and situation. Patients need guidance to find new methods to cope with their difficult situation. When the patients' own resources are insufficient, and when they are subjected to multiple painful treatments, the nurses need to take action.

### *Body image after burns*

The results of our studies include descriptions of changes in body image, as experienced by burn patients. The changes of *body reality* – the real physical body – can be described as being like getting a new and fragile body. The new fragile body leads to changes in *body presentation*, or how we present our body appearance. The patients' experiences describe how they partly lose control of body presentation and also reflections on how body presentation is received or perceived by other people. *Body ideal*, how we think we should look, involves the individual – consciously or otherwise – measuring body reality and body presentation against a standard norm (90). The changes of *body ideal* after burns involve both patients' dissatisfaction with their appearance and interaction with other people.

### *Fragile Body*

In our study, description of the new fragile body, and its impact on daily life post-injury, emerged from the narratives. The new and demanding body was described as being sensitive to new stimuli that triggered pain. The new body was perceived as fragile and lacking durability for daily tasks, clearly impacting on daily functions. Several activities required careful planning and the new body was no longer strong and something to be relied on.

The new and demanding bodily awareness after burn injury is also identified in other studies (54, 80). Patients are going through a new experience of losing the familiarity of their bodies, being unwilling to investigate the possibility of feeling love, being hesitant and resisting habitual actions as well as being insecure and distrusting one's own abilities (54) and loss of control and self-esteem of the body (80). Interacting with the source that caused the burn injury, for example, heat, leads to anxiety, and is described previously in the literature (54, 80). This anxiety was also described by patients in our studies (papers II and IV) where many patients avoided situations with exposure to heat, which led to less home-cooked meals and a change in eating habits. This was something the patients discussed with the burn nurse at follow-up.

One reflection that emerged during our study is that the fragile body may also be a metaphor to describe the spiritual healing of patients. The body may serve as a reminder of what had happened in the accident, as well as during hospitalization and rehabilitation. It is often easier for all parties to apply a more comprehensible, physical metaphor to discuss such issues. The fact that burn care is focused on physical healing and is also perceived by caregivers as being either successful or unsuccessful, depending on how the wounds are healing, reinforces the role of the body as a mediator of health.

### *Body image dissatisfaction*

In our study greater body image dissatisfaction was found for female gender, patients with more extensive burns (TBSA) and deeper burns, results that are similar to those found in other studies which have assessed body image dissatisfaction by applying the Satisfaction with Appearance scale (51, 91). Calota et al (91) found in a pilot study that female gender was a significant marker for body image dissatisfaction in patients with severe burns. This outcome was evident for the female gender, even with those having burns in less exposed areas.

Further to a study by Claota et al (91), it was reported that patients with visible scars (on the hands and face) have significantly greater body image dissatisfaction. This finding was not evident in our study, perhaps due to a lower rate of severe burns. Another reason could be that in our study a criterion for "visible burns" included only burns on the face and neck. However, we found that patients with moderate burns had significantly more body image dissatisfaction and this classification included patients with deep hand burns. We also found that patients who underwent surgery during care had more body image dissatisfaction. This was not investigated in the studies by Thombs et al and Calota et al (51, 91), however all the patients in the study of Calota et al underwent surgery during care.

The evidence of whether severity of injury or large burns (TBSA) lowers body esteem and results in greater dissatisfaction with appearance is still questionable. It must also be noted that TBSA is an estimation of the sum of partial and full-thickness burns, usually performed in the acute phase and it is not an outcome measure in the sense of esthetic and functional outcome (58). The reason for this evidence gap is probably, in part because few studies have quantitatively measured body image or satisfaction with appearance, especially over time. Other reasons are that study groups are often small.



Bowden et al found that the size of the burn did not seem to significantly affect self-esteem (92). Lawrence et al found that social and emotional variables are more important than burn severity and characteristics in determining body esteem among burn survivors (50). The subjective rating of burn severity had a higher correlation with body esteem than more objective measures of burn severity such as TBSA, number of surgeries or scarred body parts (50).

About seven months post-burn, the level of socialization becomes more challenging and disfigurement become evident. In our study we measured body image dissatisfaction at one time point, three months after discharge, but our results at that time-point were almost the same as those consistently relate to one aspect of body esteem: attributions of others (50). Visible scarring is associated with greater distress with more frequent startled and confused behavior (50), causing negative social reactions of others (7). There is a controversy around whether it is more difficult to cope with visible or with hidden scars (50). One hypothesis is that people with facial scars get more accustomed to stigmatization behaviors and learn coping strategies than those with hidden scars.

There are two studies that have investigated body image dissatisfaction over time (51, 91). In both studies, SWAP increases at the baseline up to the six-month follow-up and then slowly decreases at the 12-month follow up. This finding supports the theory of adjustment to disfigurement by Partridge and Thompson (57), indicating that in the first months after burn injury the patients are focusing on physical found in the study of Thombs et al (51) at six months after discharge. In our pre-test and validation of SWAP (paper III), the patients also pointed out that those thoughts about body image depend on the length of time that has passed since the injury, and how far one has personally developed in the adaption after the injury.

The difference in body image dissatisfaction between men and women is interesting and could have clinical significance. In the pre-test (paper III), several respondents believed that unattractiveness of the burn to other people was different for men and women. According to respondents in our study, it is more difficult for women to have wounds and scars. This difference may be due to current body ideals, especially for women who are expected to be young, slim, attractive and healthy-looking and this element of self-image seems to be more important for younger women than for older women. Previous studies confirmed that women feel more shame related to their new body after burns (93) and that women are more likely to attend extended reconstructive surgery (55), indicating that similar burns can cause more psychological distress in women than in men.

We found that body image dissatisfaction could potentially predict the risk for posttraumatic stress disorder at the three-month follow-up. To confirm this finding, the study must be replicated with a larger sample to investigate if body image dissatisfaction could facilitate posttraumatic stress syndrome and justify causal inferences. A review of the literature about the role of disfigurement concluded that disfigurement can be a reminder of the trauma and subsequently maintain PTSD, but the evidence is lacking (58). Fauerbach et al (53) also found that patients with greater body image dissatisfaction have significantly lower psychosocial adjustment at two-month follow-up. Furthermore, a negative body image has been shown to be the most salient predictor for psychosocial function in patients with burns at a 12-month follow-up and also mediated the relationship between pre-burn and post-burn psychical function (51).

Identification of early body image dissatisfaction could possibly determine subsequent psychological stressors for patients with burn injuries. Routine screening of perceived body image during the hospital stay would be helpful to identify patients who need additional support. The Swedish version of the Satisfaction with Appearance Scale (SWAP-Swe) seems to be a reliable and valid instrument for use in a Swedish-speaking population. It is easy to use in the clinical setting because it is short, and is well understood by the patients.

### *Posttraumatic stress disorder*

There is growing knowledge of the psychological stress after burn injuries. Posttraumatic stress disorder is one of the most prevalent psychological problems affecting approximately 45% of burn patients (58), 18-35% within the three-month period post-burn. Our results show a slightly higher prevalence rate in this finding than was shown in the literature (paper IV).

It is, however, difficult to compare prevalence between studies due to different methods of assessment, sample characteristics, the diagnostic criteria used and variation in the timing of assessments (58). Some studies include patients with pre-injury psychiatric problems that are a significant factor for the development of PTSD. In our study, we excluded patients with known mental illness. One-third of the patients however, had pre-injury psychological stress (e.g. anxiety, alcohol or drug abuse or stress caused by other traumatic events), which may affect the prevalence of PTSD.

It is of importance to consider which instrument is used for the assessment of PTSD and there are several global self-reported questionnaires that are appropriate to use in burn care. The instrument used in our study (IES-R) is empirically validated to use for Swedish burn patients (74). Furthermore, there is a discrepancy between methods of structural diagnostic interviews and self-reports, showing that at the one-year follow, up studies using diagnostic interviews find greater prevalence than studies using self-reported measurements. Nevertheless, interviews in the literature included patients with pre-morbid psychiatric disturbances (58). Thus, interviews assess the syndrome of PTSD while self-reported questionnaires measure the intensity of symptoms and rely on cutoff points to determine PTSD (58). In our study we did not provide the diagnoses of PTSD by diagnostic interviews. As a consequence, there may be up to 50% false positive results in our study, but the risk of missing false negative results is very low according to the study of Sveen et al (74). Patients at risk of developing PTSD were referred to a psychology clinic and it was confirmed that the majority of these patients did suffer from PTSD or had intensive stress symptoms.

We found in our study that the total IES-R scores and the three subscales had a tendency to decrease over time and this was significant to subscale intrusion. According to the literature, PTSD symptoms do not decrease noticeably during the first year after trauma (58, 94, 95). There is some clinical evidence by professionals working with PTSD that intrusion can decrease with time (59) and the literature confirms that early diagnosis and intervention prevents illness from becoming prolonged (59, 96). The decrease of the scores over time in our study may be a result of the psychology treatment to which the patients were referred early in the follow-up period.

Our findings of risk factors for PTSD are confirmed by previous literature; length of hospital stay, surgery, existing pain and nightmares (58, 95, 97). There was a tendency for women and those with deep burns to have a higher risk of developing PTSD in agreement with the literature (58, 98). In our study, body image dissatisfaction was found to be a risk factor for PTSD, but the evidence of this is not well documented in the literature so future longitudinal studies are needed to discover what role that disfigurement plays in the development of PTSD.

The relationship between severity of burns and TBSA was not evident in our study, where the majority of patients with PTSD had minor or moderate burns. This was a surprising result but is in agreement with literature where severity of burns and TBSA have been demonstrated to be of minor importance in relation to PTSD (58). When discussing the risk of developing PTSD with the patients, it was more evident that the patients' situations were strained. Interestingly, a high level of anxiety related to pain as well as painful treatment of burn injury are both found to enhance the risk of PTSD in the literature (58), as are anxiety and dissociation during the accident. These descriptions are illuminated by the patients in our studies I and II, and it can be assumed that this experience is stress-related.

### *Coping and adaptation to life after burns*

Coping and adaption are discussed together due to the difficulties in separating these processes from each other, both in the results in this study as well as in the literature. Seeing adaptation as a concept that includes coping strategies, emotions, actively changing routines and models of getting along (60), it can be described in the light of patients' experiences. Lazarus demonstrates (60) that emotions play a significant part in adaptation and that they are thoroughly intervened and one cannot be fruitfully described without reference to the other. Coping is involved in the emotional process from start to finish as it is an integral part of the process of emotional arousal (60). Stress, emotions and coping exist together in a relationship with each other and can, together, ease the adaption process.

In our studies (papers I and II), informants used a variety of coping strategies to manage burn care and daily life after discharge. In response to a stressful situation, an individual often uses a variety of coping strategies (62). Even if we today have fairly standardised treatment protocols, the results from our study show that burn patients manage pain and anxiety on their own on daily basis to a large extent. To endure and carry out these experiences, patients used many coping strategies. One common strategy found in the literature was avoidance and denial, inducing feelings of anxiety and hopelessness, which are emotions significantly related to avoidance coping (65). In the study of Moi et al (99), to endure the burdens of the burn injury as part of the treatment was found to be essential for the patients, in agreement with our study.

Avoidance coping also includes descriptions about denying family the right to visit and to be part of the care. Lazarus illustrates (60) that denial can also be a useful strategy when nothing can be done to alter the illness, or prevent further harm and that it could be beneficial at the hospital. Temporary avoidance may be useful in dealing with uncontrollable or overwhelming symptoms during the acute phase of recovery from burns (62), but it is related to poor psychological and physical outcomes (63, 66) and

more symptoms of depression and PTSD (64, 65, 100) beyond the period of hospitalization, a result which was also found in our study. Using avoidance may lead to distress and contribute to those depressive symptoms persisting if the person defers seeking help (64).

Being active, engaging in care, taking part in training and setting new goals, and optimism/problem solving, were described in our study by patients to be important elements of the recovery process. Being physically active, standing, and walking were recognised as a positive turning point for the informants in the study of Moi et al (54).

In our study, emotional support, keeping company with staff, and friends and relatives acting as a bridge between life in hospital and the outside world helped patients to find meaning and look forward. The literature shows that optimistic attitudes and social support might positively influence patients' compliance with medical procedures and lead to resilience when confronting situations of substantial psychological distress (101).

To maintain normality and find routines, as described by informants in our study, self-control can both be both a positive and negative influence for the patients. To limit emotions in order to endure a difficult or overwhelming situation (60) can be part of "carrying the pain" and managing the care. The person who controls himself has a greater tendency to experience loneliness and not sharing feelings with others can inhibit the adaptation (66). Self-control can also depend on the possibility of getting help. Individuals cope differently with disability and there are no orderly stages of adaptation following trauma (45), making it more difficult for professionals to meet patients' needs. Some patients in our study described also that they did not realise their need for help during hospital care but that this became obvious after coming home.

Factors that may complicate adjustment in our findings were noncompliance with staff and lack of psychological support and information. In a recent study on patient satisfaction, Wikehult et al. (81) also reported that lack of treatment information was common among burn victims. Another study evaluating the perceived skills of health care professionals in burn care reported that they rated their skills in advising patients about physical items higher than those for psychosocial items (102). Furthermore, skills in giving physical advice were found to have increased with years of experience in burn treatment while skills in psychosocial care remained unchanged (102).

Patients used many coping strategies to cope with disfigurement in our study. The greatest correlation was found for avoidance and coping for social discomfort and social impact of the new appearance. Similar results were found by Feuerbach et al (103) two months after discharge. Frequent use of emotion-focus coping (mental disengagement and venting) was related to significantly higher body image dissatisfaction, especially for the aspect of social impact (103). This result is further confirmed by Amayal et al (104) where avoidant coping strategy had a positive correlation with the total SWAP score immediately after discharge and at six and twelve months after discharge (104). This finding could imply that Avoidant coping maintains distress with body image changes and that the patients need help to actively start processing bodily changes after the burn injury. Furthermore, it seems that women are in the risk zone of using maladaptive coping, or avoidance, when dealing with disfigurement after burns, which we also found in our study.

Generally, when coming home, patients try to re-evaluate and adjust to life by working through trauma, fighting to adapt, and partly becoming accustomed to it. The burn injury was seen as a long healing process leading the new perspectives. This perspective was also found in the study of Moi et al (99) where feeling grateful for being alive with new understanding imposed by the injury led to a revision of life. At the same time, patients were putting all of their efforts into regaining freedom, and aiming for a return to life as it was before (99).

Revaluation/adjustment in our findings includes the entire images, both negative and positive experiences and, in light of these, seeing life in a new perspective. In addition to taking advantage of the experience, patients were found to see the trauma in a perspective that was more acceptable to them (66). They tended to focus more on what is really important in life, such as family and friends, but also to see that there are other people who have it worse. This coping strategy includes partly forgetting the trauma, or not thinking about it, in order to obtain the energy to focus on other important things in life. This is a sense-cognitive process and may be evidence of expressions of internal adjustment.

There are also a number of patients who experience burn trauma with no apparent existential crisis or difficulties in coping. Results show that besides the major negative impact associated with the experience of a severe burn injury, such an aversive experience can also lead to positive change and greater sense of personal strength (105).

Personality, especially neuroticism (64), pre-injury psychological status and social support such as family relationships, are important factors for adaptation to injury after burns. These aspects were not investigated in this study, which might have influenced the results. Seeing coping as a process, which can change over time, requires longitudinal studies with repeated measurements. This could facilitate the interpretation of coping profiles and illustrate patterns of how burn patients are adapting over time. In our study, coping was investigated at one time point and was described by narrative data (on average 7 months post-discharge) and in relation to outcome measures as body image disfigurement and posttraumatic stress disorder three months after discharge. This limited the possibility of making further interpretations of coping dynamics as the adaptation process continued.

# METHODOLOGICAL CONSIDERATIONS

## TRUSTWORTHINESS IN PAPERS I AND II

Papers I and II use a qualitative approach and strive to interpret and create meaning and understanding of the subjective human experience of a phenomenon in its specific context. Kvale and Brinkman (76) hold that, “If you want to know how people understand their world and their lives, why not talk with them?” This may seem simple, but a qualitative research interview is not a conversation between equal partners, but instead a conversation with structure and purpose. To some extent, the interview is one-sided where the researcher controls an instrumental dialogue and has a monopoly on the interpretation (76).

In papers I and II, the methodological considerations refer to trustworthiness in the form of credibility, dependability, confirmability and transferability. *Credibility* refers to confidence in the truth of the data and interpretations of data (106), and how well the data and progress of analysis have the intended focus of the context aimed at in study. The purposive samplings (106) in our studies were used based on the researchers’ knowledge about the population. To some extent, a strategic selection was also made in accordance with the inclusion criteria for the study. Since the majority of burn patients were men, letters were sent to as many women as possible to achieve a more balanced gender representation in the study. The composition of respondents in this study reflects reality, in which two-thirds of burn patients are male. One strength of the mix of respondents in this study was that they had a variety of injuries, different lengths of hospital stay, different social situations and were in various stages of life. Such circumstances may have enriched the narratives on pain and how patients coped with stressors and adapted to new situations. The sample consisted of 12 patients, and based on data saturation, the point at which no new information was obtained and redundancy was achieved (106).

Important methodological questions, such as how to ask a variety of questions, how to initiate the interview process, how many patients to interview, how to avoid prejudicing the respondent with leading questions, and whether interpretations will be subjective (76), were posed prior to data collection through interviews. An interview guide was drafted for semi-structured interviews in which the research question and the area were indicated, and the interview always opened with the same question. Having predetermined topics for the interview may have increased the homogeneity of data collection (73). The focus of the studies was to elucidate the “core” of the phenomenon and its character. A strategic choice was made in the sense that we selected respondents who had experience of the area of research. To test validity the principal supervisor (YW) listened to the first interview, and several interviews were discussed to identify new questions raised.

A text never implies one single meaning, just the most probable meaning from a particular perspective. Thus, our interpretation should be considered as one possible interpretation of the experiences of pain and adaptation to life after burns. The large volume of text material demands careful review to structure the narrative so that the

purpose is illuminated. Two researchers (OD and YW) were involved in the analytical process which strengthens the *dependability* of the studies.

To enhance *confirmability*, congruence between independent people about the data accuracy, meaning and reflection of the informants voices (106), every step in the analysis process was discussed until consensus about the interpretation was achieved. The findings were also reflected in relation to the interview text and the literature.

Only the author was aware of the context specific to the burn injury, but having different pre-understanding of the phenomenon was no obstacle; instead it allowed for a change of perspective and gave momentum to the analysis. However, this element could also be seen as a strength because it contributed to a consistent structure in interviews, and the same areas of questioning were asked to all the informants.

My experience of burn care as a nurse probably facilitated my interpretation and helped to create an overall picture of the narratives. My knowledge of the conceptual content may have led me to view burn pain and coping as it is described in the literature and not to recognise new descriptions, which may have influenced text categorization. Knowledge of the nature of care also influenced me to interpret the interviews from a nursing perspective and not objectively from a patient perspective. On the other hand, I was open to the contextual knowledge that I lacked: knowledge of what it means to be in pain and to deal with the consequences of the burn injury. The fact that I did not personally provide nursing care to the respondents in this study was an advantage.

To achieve *transferability* (106) of this study, sufficient descriptive data have been provided about how burn patients experienced and cope with pain and psychological stress after the injury. Descriptions have rarely any intrinsic value but win their legitimacy when they can generate understanding of the phenomena which can be transferred to other settings or groups (107). This can be partly done by readers who may evaluate the applicability of the data to other contexts (106).

## **VALIDITY, RELIABILITY AND GENERALISABILITY, PAPERS III AND IV**

An important question in all studies is the sample and selection of patients. This element affects both internal validity (reliability of the results and the extent to which one can draw conclusions) and the generalizability of results from a sample (external validity) (73).

Most studies of pain and psychological stress are based on samples of patients from local burn units and response rates are low which can lead to bias in the studies.

Logistically, it is very difficult to study burn patients after discharge. Due to over-presentation of individuals with history of psychopathology among these patients, it can affect the response rate in studies because the contexts were meaningful and familiar for the patients.

The sample was based on populations in catchment areas for the hospital. Selection bias was limited by including all eligible patients treated at the Department of Reconstructive Plastic Surgery, Karolinska University Hospital, at the time of the

study. The response rate in Paper III is in line with previous studies investigating body image dissatisfaction (51, 103, 108). To facilitate the participation for patients in the study, we offered two options to participate, that is, to either meet in a focus group or to participate in individual interviews. The choice was made based on our clinical experience that not all burn injury patients are comfortable meeting other persons with burn injuries. Respondents in the pre-testing phase had more severe burns than those in the population chosen to test the psychometric properties of the questionnaire, but this could be a strength of the study, as these particular patients have experiences of several aspects of body image dissatisfaction.

The response rate in study IV was higher compared to other follow-up studies in the same research field (58). A comparison between respondents and non-respondents found one significant difference; the presence of visible scars (face and neck) was significantly higher in the respondents. Attrition between the three- and six-month follow-up affects the measurement of risk of PTSD, however, our findings are in agreement with the literature. During the study period the care conditions for burn patients changed because the burn care unit moved to another hospital. This relocation may have had an impact on the participation in the follow-up visits, with a loss of patients due to administrative reasons, making it more difficult to have regular contact with the patients.

Demographic data were collected from medical records. Severity of the injury is one profound character of burn patients and it depends on several factors that have an impact on daily life; such as depth and localization of burns, age, medical conditions and demands on burn care. However, there are difficulties comparing results from different studies with respect to the severity of the burn injury. Definition of the severity is often lacking in the studies. Most studies used the burn center referral criteria by ABA which is very general. In studies III and IV, we reported the severity index by the Swedish National Board of Health, which is more suitable when studying outcomes as stressors because it takes into account several important factors. Respondents in studies III and IV had mostly minor and moderate burns and less extensive TBSA rates than some other studies about PTSD, BID and coping. Nevertheless, TBSA has not proven to have a crucial role in the outcomes of our studies.

Information about educational levels was not collected, which could be a confounder, but there is no evidence that this demographic is associated to the stressors investigated in our study.

There are several global self-reported questionnaires for the measurement of posttraumatic stress disorder, body image dissatisfaction and coping. The psychometric properties of the self-reported questionnaires used in our study have been analysed in burn populations (66, 74, 109). This may have increased patient compliance and motivation when used in clinical settings because the context was familiar for the patients.

The Satisfaction With Appearance Scale (SWAP) is designed for patients with burns and includes both subjective appraisal as well as social-behavioral aspects of body image (75). We hypothesised that SWAP could partly measure the three aspects of body image. The body reality can be assessed by questions about how satisfied the



respondents are with appearance in the different parts of the body (items 4-11). The body presentation (behavior and reflection on how the body is received by the environment) and the body ideal (how an individual desire to appear and responses from society) can be accessed through questions about attractiveness of body and thoughts how it can be perceived from other people's point of view (items 14-15). There is no validated or clinically identified cutoff point for body image dissatisfaction and SWAP. Thus we have only assessed SWAP-scores in correlation to other outcomes and not grouped respondents with respect to body image dissatisfaction.

One of the aims in the study was to translate, culturally adapt, and assess the psychometric properties of SWAP in Swedish-speaking burn population. Mixed methods were used and the choice to adopt these methods was made due to the fact that the questionnaire (SWAP) was new in the context of burn care in Sweden, which was why a qualitative exploration was needed before it could be used for clinical applications (106). Qualitative and quantitative data were collected in different phases of the study but the results were integrated with empirical findings (110). Several steps were carried out that are important to obtain an adequate and validated result. First, translation and back-translation was carried out by two independent accredited translators according to the guidelines from the literature (111). Secondly, *face validity* was assessed by proposed respondents (burn patients) and consultation with experts (a committee of professionals in burn care) to test and verify the words used in a given context and how they might be understood and interpreted by different persons. Thirdly, experiential and conceptual equivalence were evaluated for the questionnaire. Factor analysis, describing *construct validity*, was carried out with 90 respondents which is satisfactory according to the literature (112), that recommends five respondents per item as a rule of thumb.

One limitation in the analysis in paper III is the lack of a reliability test (test-retest). The stability of the SWAP-Swe could not be tested, and this is of particular importance when assessing changes over time or responsiveness (112).

## CONCLUSIONS AND CLINICAL IMPLEMENTATIONS

Learning about patient experiences, as they have been described, is one path to deepening health care professionals' understanding of these experiences and to allow them to learn to integrate their meaning into burn patient care. Self-described coping and adaptation processes that emerge from the patients' perspectives can also serve to inform coping rituals as well as assist other burn patients in understanding their own recovery.

A multidisciplinary team approach for the pain treatment needs to be prioritised. The results indicate that there needs to be an increased focus on and development of pain treatment for burn injury, especially around burn wound care procedures.

Satisfactory pain treatment would conserve the patient's strength to carry out more of their daily activities and increase the patient's own participation and control of care.

To endure the burdens of the burn injury as part of the treatment was found to be essential for the patients. Psychosocial support needs for patients treated for burns should be implemented in the future to support coping and to increase the patients' ability to adapt to burn injury. The nurse is in an optimal position to support and encourage the patient's independence and self-care, but to make this feasible the nurses may need guidance to increase knowledge of coping strategies and to help the patient find new ways to cope with this stressful situation. A psychologist should be added as a natural part of the burn care team, both to address the stresses faced by patients and also to support burn team. One possible application of the results may be to identify potential risk groups early on; for example, those patients who use coping strategies associated with poorer adaptation, such as avoidance (isolation, daydreams, wishful thinking). This type of coping may prevent proper processing of the accident and sustain psychological stress after burns.

Many areas for improvement are to be found in the burn care process, such as informing and involving patients in care to a higher extent. To facilitate this involvement, patients need adequate information about what has happened to them from a purely physiological stance, what emotions may arise and the care they can expect. Both patients and family need to be knowledgeable about the care environment to make it easier to adapt to it, although this proved to be an important source of support for the patient throughout the care and recovery process.

Disfigurement is a stressor after burn injury, affecting the patient's social interaction with other people and adding to their psychological stress. Particular attention should be directed towards the female patients' and patients with more extensive burns. Body image dissatisfaction could be assessed even during the care given at a baseline and differences in responses over time this could potentially predict the risk of PTSD. The Swedish version of the Satisfaction with Appearance Scale could be implemented in the clinical settings as it has proven to be valid and well understood by the patients.

Members of burn teams need to be trained to improve and sustain key competencies in the area of social adjustment after disfigurement. Guidance for improving self-

presentation in social interactions as well as support to adjust and find a new body image and build self-confidence would be an appropriate task for the burn nurses.

In clinical practice, with limited time and resources, it becomes increasingly important to follow up after the care of burn patients. Our findings suggest that it is important to also follow patients with less extensive burns because this group is also at risk of the development of PTSD and body image dissatisfaction. Early follow-up should include both standardised questionnaires and clinical protocols to capture aspects that can add or affect the stress as ongoing pain, nightmares and body image dissatisfaction.

Being assigned with a contact nurse, a specialised burn nurse, could be a valuable function to complement the follow-up of burn patients throughout the care trajectory.

## FUTURE RESEARCH

The knowledge that burn injuries produce both physical and psychological problems during their care and long after hospital discharge sparks an interest to continue to improve pain treatment and provide evaluating follow-up programs for these patients.

Effective management of burn-related pain needs further attention. This complex problem demands matching appropriate interventions to each individual patient. Many non-pharmacological pain relief methods (e.g., hypnosis, diversion, guided imagery, relaxation) may potentially complement treatment and need to be implemented in burn care. The benefit of treatment that combines these methods with pharmacological treatment should be illuminated by research. These treatments could be implemented in multicenter studies to increase sample size and to avoid the effect of having various different treatment methods employed at different burn units.

Longitudinal follow-up after burn injuries is needed to improve rehabilitation and to identify different models for follow-up. To do that, effective development and implementation of valid instruments for patient-reported outcomes needs to be in place. The questionnaires need to be used in both in- and outpatient settings to clarify the link between early and subsequent body image dissatisfaction and its development over time. This element also needs to be tested in different burn populations to increase evidence of groups at risk of body image satisfaction. To complement the knowledge of the strain of disfigurement, the assessment of perceived stigmatisation and social comfort need to be added in follow-up treatment. Interventions to address an altered appearance need to be integrated (e.g. STEPS, CBT, prevention support, psychological interventions) and evaluated in the rehabilitation programme. As a complement to the multidisciplinary follow-up programme, specific nursing follow-up programmes to support patients can be improved and evaluated.

Multicenter studies, including several burn units, and a national database register for burn patients could be of benefit to increasing research evidence to implement in clinical practice. This will not only increase sample size and statistical power but will also detect significant markers for risk factors that may be of clinical importance.

# POPULÄRVETENSKAPLIG SAMMANFATTNING

## BAKGRUND

Brännskada innebär fysiska och psykiska trauman för den drabbade personen. Patienter som behandlas för brännskador upplever ofta höga nivåer av smärta och ångest i samband med behandlingar under vårdtiden. Första året efter utskrivning från sjukhuset är en psykologiskt ansträngande period för patienten. Patienterna kämpar med stressreaktioner efter traumat, minnen av olyckan, förändrat utseende och dagliga problem med fysiska begränsningar efter brännskadan. Den brännskadade kroppens känslor och utseende förändras efter skadan, och ömtålighet samt kroppsuppfattning kan vara förändrad en lång tid efter skadan.

Psykisk återhämtning kan beskrivas i form av anpassning till livet efter skadan. De flesta brännskadepatienter anpassar sig väl till livet efter brännskada men för vissa patienter med oförmåga att hantera stressfyllda och känslomässigt krävande situationer (coping) kan psykiska symtom bli långvariga.

## SYFTE

Det övergripande syftet med denna avhandling var att undersöka patientens upplevelse under vården med fokus på smärta, kroppsuppfattning, posttraumatiskt stress och coping samt utforska anpassning till livet efter brännskada

## PATIENTER OCH METODER

Avhandlingen består av fyra olika studier var olika metoder har använts för att få en bredare bild över patienternas upplevelse av vård och vad det betyder att ha brännskador. Studierna har inkluderat patienter vårdade på Kliniken för Rekonstruktiv Plastikkirurgi på Karolinska Universitetssjukhuset.

I studie I och II intervjuades 12 vuxna brännskadepatienter 6-12 månader efter utskrivningen om upplevelser av smärta, coping and anpassning till livet efter skadan . Studie III fokuserade på att kulturellt anpassa ett frågeformulär till svenska förhållanden för att mäta kroppsuppfattning och tillfredsställelse med utseendet efter brännskada. Frågeformulärets användbarhet testades med 13 patienter genom fokusgrupp möte och intervjuer. Därefter utfördes statistiska tester för att mäta tillförlitlighet genom att frågeformuläret besvarades av 90 patienter. I studie IV erbjöds alla brännskadepatienter, vårdade inom slutenvård, ett uppföljningsbesök 3, 6 och 12 månader efter utskrivningen. Ett standardiserat kliniskt protokoll användes för systematisk bedömning av posttraumatiskt stress, kroppsuppfattning och tillfredsställelse med utseendet samt copingstrategier. I uppföljningen ingick besök hos

kontaktsjuksköterska för brännskadepatienter som ett komplement till det befintliga programmet. Totalt deltog 52 vuxna patienter med olika svåra brännskador vid tre månaders uppföljningsbesök och 32 patienter fullföljde sex månaders besök.

## RESULTAT

Samtliga patienter hade klara minnesbilder av smärta och upplevde svår smärta under vårdtiden. Många av de dagliga åtgärderna i vården, särskilt sårbehandling, upplevdes som smärtsamma av patienterna. Generellt under vårdtiden handlade coping om att försöka uthärda smärtan. Patienter skildrar livet efter skadan som en kamp, att leva med konsekvenserna som består av att på olika sätt handskas med nya förutsättningar med en ny, bräcklig och förändrad kropp och känslomässig bearbetning av traumat. Anpassningen sker delvis genom reflektion och genom att skapa distans till brännskadan samt förändra prioriteringar och målsättningar i livet för att känna sig hel igen.

Det finns många förbättringsområden inom vården för att på bättre sätt stödja dessa patienter. Den svenska versionen av frågeformulär för att mäta kroppsuppfattning och tillfredsställelse med utseendet (Satisfaction with Appearance Scale-Swe) visade sig vara ett tillförlitligt instrument för bedömning.

Kvinnor och patienter med medelsvåra brännskador samt dem som opererades under vårdtiden var mer missnöjda med kroppens utseende efter skadan.

Ungefär hälften av patienterna hade en risk att utveckla posttraumatiskt stresstillstånd tre månader efter utskrivning från sjukhus. Denna risk var relaterad till längre sjukhusvistelse, genomgång av operation, smärta, mardrömmar och mer missnöje med kroppens utseende efter skadan.

## SLUTSATSER OCH KLINISK IMPLEMENTERING

Utveckling av effektiva smärtbehandlingsmetoder för vården av brännskadepatienter är av yttersta vikt. Program för psykosocialt stöd behöver förbättras för att öka patienternas förmåga att delta i sin egen vård och för att underlätta anpassning till livet efter skadan. Särskild uppmärksamhet bör riktas för kvinnliga patienter och patienter med mer omfattande brännskador då dessa är i större risk för ökat missnöjdhet med förändrat utseende efter skadan. Det är viktigt att inkludera patienter med mindre omfattande brännskador i uppföljningsprogram eftersom denna grupp är i riskzonen för att utveckla posttraumatiskt stresstillstånd. En tidig uppföljning bör omfatta standardiserade frågeformulär för att fånga aspekter som kan leda till ökad stress, som till exempel smärta, mardrömmar och förändrad utseende och kroppsuppfattning.

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# Appendix I

## Satisfaction With Appearance Scale

Patient: \_\_\_\_\_ ID #: \_\_\_\_\_ Date: \_\_\_\_\_

In each of the following statements, circle the most correct responses for you according to the following scale:

- 1 = strongly disagree
- 2 = disagree
- 3 = somewhat disagree
- 4 = neutral
- 5 = somewhat agree
- 6 = agree
- 7 = strongly agree

1	2	3	4	5	6	7	Because of changes in my appearance caused by my burn, I am uncomfortable in the presence of my family.
1	2	3	4	5	6	7	Because of changes in my appearance caused by my burn, I am uncomfortable in the presence of my friends.
1	2	3	4	5	6	7	Because of changes in my appearance caused by my burn, I am uncomfortable in the presence of strangers.
1	2	3	4	5	6	7	I am satisfied with my overall appearance.
1	2	3	4	5	6	7	I am satisfied with the appearance of my scalp.
1	2	3	4	5	6	7	I am satisfied with the appearance of my face.
1	2	3	4	5	6	7	I am satisfied with the appearance of my neck.
1	2	3	4	5	6	7	I am satisfied with the appearance of my hands.
1	2	3	4	5	6	7	I am satisfied with the appearance of my arms.
1	2	3	4	5	6	7	I am satisfied with the appearance of my legs.
1	2	3	4	5	6	7	I am satisfied with the appearance of my chest.
1	2	3	4	5	6	7	Changes in my appearance have interfered with my relationships.
1	2	3	4	5	6	7	I feel that my burn is unattractive to others.
1	2	3	4	5	6	7	I don't think people would want to touch me.

*Note.* Items 1–3 and 12–14 adapted from "A Burn Specific Health Scale" by B. Blades, N. Mellis, and A. M. Munster, 1982, *Journal of Trauma*, 22, p. 872–875. Copyright 1982 by Andrew M. Munster. Adapted with permission.

## Appendix II

### SWAP- Swe (Satisfaction With Appearance Scale- Swedish version) **Bedömningsskala för tillfredsställelse med utseendet**

ID-nr: \_\_\_\_\_ Datum: \_\_\_\_\_

För varje påstående ringa in det svar som bäst passar in på dig enligt följande skala:

- 1 = håller inte alls med
- 2 = håller inte med
- 3 = håller inte med helt
- 4 = varken eller
- 5 = håller delvis med
- 6 = håller med
- 7 = håller verkligen med

1	2	3	4	5	6	7	På grund av förändringarna i mitt utseende genom brännskadan känner jag mig besvärad tillsammans med min familj.
1	2	3	4	5	6	7	På grund av förändringarna i mitt utseende genom brännskadan känner jag mig besvärad tillsammans med mina vänner.
1	2	3	4	5	6	7	På grund av förändringarna i mitt utseende genom brännskadan känner jag mig besvärad tillsammans med främmande personer.
1	2	3	4	5	6	7	Jag är nöjd med mitt utseende totalt sett.
1	2	3	4	5	6	7	Jag är nöjd med utseendet på min hårbotten.
1	2	3	4	5	6	7	Jag är nöjd med utseendet på mitt ansikte.
1	2	3	4	5	6	7	Jag är nöjd med utseendet på min hals.
1	2	3	4	5	6	7	Jag är nöjd med utseendet på mina händer.
1	2	3	4	5	6	7	Jag är nöjd med utseendet på mina armar.
1	2	3	4	5	6	7	Jag är nöjd med utseendet på mina ben.
1	2	3	4	5	6	7	Jag är nöjd med utseendet på min bål.
1	2	3	4	5	6	7	Förändringarna i mitt utseende har påverkat mina relationer.
1	2	3	4	5	6	7	Jag har en känsla av att brännskadan är oattraktiv för andra.
1	2	3	4	5	6	7	Jag tror inte att folk skulle vilja röra vid mig.

